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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 1999

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HEARINGS

BEFORE A

SUBCOMMITTEE OF THE

COMMITTEE ON APPROPRIATIONS

HOUSE OF REPRESENTATIVES

ONE HUNDRED FIFTH CONGRESS

SECOND SESSION

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SUBCOMMITTEE ON THE DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES

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S. Anthony McCann, Robert L. Knisely, Carol Murphy, Michael K. Myers, and Francine Salvador, Subcommittee Staff

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PART 7B
(Pages 1-1371)

TESTIMONY OF MEMBERS OF CONGRESS AND OTHER

INTERESTED INDIVIDUALS AND ORGANIZATIONS

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DEPARTMENTS OF LABOR, HEALTH AND HUMAN SERVICES, EDUCATION, AND RELATED AGENCIES APPROPRIATIONS FOR 1999

Wednesday, January 28, 1998.

TESTIMONY OF MEMBERS OF CONGRESS AND OTHER INTERESTED INDIVIDUALS AND ORGANIZATIONS

WITNESS

JEROME PAULSON, M.D., AMERICAN ACADEMY OF PEDIATRICS

Mr. Porter. This hearing begins the subcommittee's work on fiscal year 1999 funding for the departments and agencies within our jurisdiction.

Today we begin by hearing from public witnesses. We will then proceed to each of the departments and agencies, and then finally to Members of Congress. We will also receive testimony from the General Accounting Office. We have 29 days of hearings scheduled, covering just over 3 months, and we expect to have our final hearing right at the end of April.

Congress, as all of you know, is a busy place, and Members have many conflicting hearings, meetings, and other official responsibilities. However, let me assure you that while Members may not be present, your testimony is reviewed by them and their staffs and your views provide valuable information as we review the President's budget requests.

In order to accommodate as many members of the public as possible, we have scheduled over 20 witnesses for each session and are still not able to hear from all who wanted to testify. Overall, we will hear from over 200 witnesses in this segment alone. As a result, I have to enforce the rule limiting testimony to 5 minutes very strictly. My staff has acquired a

new countdown device that they are going to use, and I would ask that, as you testify, you keep this limitation in mind in consideration of other witnesses that must follow you.

I would also remind witnesses of two provisions of rules of the House. In addition to their written statement, nongovernmental witnesses must submit a curriculum vitae and a statement of Federal grant or contract funds they or the entity they represent have received.

If you have any questions concerning the applicability of this provision or questions as to how to comply, please contact this subcommittee staff.

We begin with Jerome Paulson, M.D., Associate Professor, Division of Pediatrics, Department of Health Care Sciences, George Washington University School of Medicine and Health Sciences, representing the American Academy of Pediatrics.

Dr. Paulson, we welcome you this morning.

Dr. Paulson. Good morning, Mr. Porter. I am Jerome Paulson, M.D., a member of the American Academy of Pediatrics. I am a practicing pediatrician and an associate professor at George Washington University. On behalf of the Academy and our pediatric colleagues, I would like to thank the subcommittee for the opportunity to present this statement, and I want to thank you for putting children first on your agenda this morning.

This year, as we celebrate the bicentennial of the U.S. Public Health Service, we applaud how much has been accomplished. We have conquered many diseases and disabling conditions, especially for children; for example, smallpox, and we are close to the eradication of polio.

To continue meeting the challenges ahead of new and emerging infectious diseases, food safety concerns, and costly chronic diseases, we must continue to invest in a continuum of public health activities that includes the full spectrum of biomedical, behavioral, and health services research, invests in disease prevention and health promotion, targets health care services for vulnerable populations, and educates a primary care and public health work force.

As pediatricians, we are on the front line and we see firsthand the impact of poverty and violence on the health of our children and adolescents, and we know that the future of our work force depends on the decisions we make today.

I will focus my oral remarks on a few observations from my own practice and research. The pediatric community has strived for decades to curb children and adolescents' access to and use of tobacco. Each day 3,000 children nationally begin to use tobacco. Of those people who will ever smoke, 90 percent begin before age 19. Young smokers suffer from respiratory problems and asthma, and among teens who are regular smokers, 1 in 3 will die from smoking.

As pediatricians, we counsel our patients about the addictiveness of nicotine and its detrimental health effects. In addition, we discuss with parents the impact of secondhand smoke on their children. These facts alone confirm that tobacco is truly a pediatric disease. As pediatricians, we strongly recommend adequate support for a wide array of tobacco prevention and cessation programs, including the CDC's office on smoking and health. These programs have a proven record of

success in reducing smoking rates.

Let us not forget the environmental effects of tobacco smoke. Asthma is the most common chronic disease of childhood and is frequently exacerbated by tobacco. It is a disease that is on the increase, and disproportionately affects African-American and Latino children.

According to the CDC, asthma-related costs to the health care system are continuing to grow because of increased morbidity and mortality. The current CDC projections for the year 2000 are $12.4 billion. Added to these health care costs are days lost from school for children and days away from work for their parents. However, with increased public health education, cost-effective environmental interventions and research, such as the NIH-, NIEHS- and NIAI-sponsored inner-city asthma study, asthma-related illnesses and costs can be dramatically reduced.

Injury is the leading cause of death and disability among children and young adults 1 to 44 years of age. Every day 60 children die from injuries and countless others are injured and disabled. Injury is costly on multiple levels: in theemotional toll it takes on victims and their families; in direct medical expenses, both acute and chronic; and in long-term economic costs due to the years of potential life and productivity lost, especially with respect to children.

In direct medical costs alone, injury costs the Federal Government $12.6 billion annually, and an additional $18.4 billion each year in disability and death benefits. Therefore, measures to prevent injury and reduce its severity are extremely cost-effective. The National Center for Injury Prevention and Control fulfills a unique function in this undertaking.

The Center's work addresses many types of injuries, both intentional, such as youth-perpetrated violence, and unintentional. Additional resources would enable the Center to continue its important leadership in the Safe America Program through which the NCIPC has brought together diverse public and private sector entities to develop and disseminate injury-prevention information and interventions.

The initial focus of the effort is to reduce injury among children and adolescents. Additional resources would also enable the center to expand efforts to reduce physical and sexual violence among children, produce a comprehensive youth violence prevention program, and ensure that every U.S. resident has access to the lifesaving and cost-effective services of a poison control center through national and State-specific toll-free numbers.

As scientists and investigators, pediatricians encourage research decisions to continue to remain in the hands of scientists at the CDC. But what happens to children or adolescents when he or she is injured and requires emergency services? As a participant in a project funded by the EMSC program, I know how important those dollars are in enabling us to develop the information that will improve the system of care for children and save lives.

Thank you for this opportunity to provide you with our recommendations for the coming fiscal year. We hope that we can continue our dialogue with this committee following the release

of the President's fiscal year 1999 budget. There are many important opportunities for pediatric behavioral and health sciences research. We know that you will not forget America's children.

Mr. Porter. Thank you. Thank you for your fine statement, and thank you for being reasonably close to your time limit.

Mr. Paulson. You are welcome, sir.

[The prepared statement of Jerome Paulson, M.D., follows:]

[Pages 4 - 15--The official Committee record contains additional material here.]

Wednesday, January 28, 1998.

WITNESS

MIKE MILLER, M.D., FDA-NIH COUNCIL

Mr. Porter. Mike Miller, M.D., Director of Federal Relations, Incorporated, testifying on behalf of the FDA Research Council.

Dr. Miller. Thank you, Mr. Chairman.

On behalf of the FDA Research Council, I want to thank you for the opportunity to submit testimony concerning the importance of a sustainable, predictable funding base for the NIH. Our comments in full will be included for the record.

We emphasize the importance of the NIH in improving the quality of health care for all. In past years this committee has been vitally important in addressing the funding needs of the NIH and the Council, and the entire research community is grateful for your support.

Based on the Council's assessment of challenges and opportunities the FDA is presented within the next several years, the Council supports doubling the NIH budget for the next 5 years, starting with a 15 percent increase for fiscal year 1999.

Why does the Council and NIAMS support such an increase for the NIH's budget? The answer to this lies, I believe, in understanding the goal of the entire process. It may seem obvious, but the goal of the entire biomedical research innovation and discovery process is to improve the quality of people's lives. In our detailed budgetary discussions that we had in Washington it is easy to forget that basic fact, but it is also sometimes not easy to see that the ultimate goal is a simple cure for a disease.

What everybody really wants is to be able to go to the physician, take a pill, and be cured for whatever ails them. Getting to that goal is not easy or simple. It takes a robust biomedical research system. Worldwide the U.S. is the leader in such a system, and the NIH is at its foundation.

What I would like to briefly discuss is the historical context of our current biomedical research system, because by understanding how we came to our current level of knowledge and the treatments from that knowledge, we can better appreciate the landscape ahead and better plan how we want to proceed in

the future.

Most people who support the NIH understand intuitively what potentially lies ahead, but by understanding what seems intuitive, it can help to clarify its importance and relevance to our lives, our actions, and our future.

What has been the progress of medicine for the past 20, 50, or 100 years? For example, 100 years ago, biomedical research was largely a process of observation and classification. Medical practice was largely based upon simple chemicals and even herbal extracts which have been found by trial and error over many years to have some beneficial effects.

In fact, in 1910, the AMA surveyed physicians and asked them what they thought were the most important therapies available to them. Number one on the list was ether, which enabled anesthetized surgery. Number two was morphine, a painkiller but certainly not curative. Number three was digitalis for heart ailments. Number nine was alcohol. Number 10 was mercury.

The AMA did a similar survey in 1945 and found significant advances. Number one was penicillin and the sulfa antibiotics, ether had dropped to number four, and digitalis to number five. Insulin had been discovered and was added to the list as number eight, and number ten was vitamins.

The question is: What would such a list look like if physicians were surveyed today. Insulin might still be on the list because it is very important for people with diabetes, but its form of purity has changed. Today human insulin is available through the common DNA technology. Other innovative medicines treat a variety of ailments which were not even understood in 1945, such as cancers, autoimmune disorders, AIDS, and neurological conditions. The list goes on.

One only needs to talk to friends or their children to find out what kind of medicines are being taken that are available today that were not available 5 or even 10 years ago. What has changed in the past 20 to 50 years? Someoutstanding biomedical breakthroughs have taken place to lead to these new medicines. Heart disease, for example, is based on--new treatments for heart disease are based on a better understanding of specific receptors or enzymes, how they block or activate those enzymes or receptors. Each of these advanced treatments is only possible once it is understood how the receptor enzyme controls some aspect of health or disease. This is the essential basic research which NIH supports. Without this knowledge, new medicine would only be found through serendipity, not through rational science.

I may have given the impression with my oversimplified account simply that innovation proceeds in a linear, stepwise fashion. It is actually sinuous and weblike, with many blind paths and interlinking discoveries. With NIH in the lead identifying promising paths, the other partners in the process will be able to support the intellectual discoveries made possible by NIH funding, and to work with NIH and academic researchers to take these discoveries out of the test tube and into a form where they can provide significant benefits to millions of Americans.

To accomplish this, support for the NIH must be across its range of programs, including those which provide means so everyone in the community can take advantage of scientific

opportunities. One other exciting avenue which is just beginning to be explored involves the race to develop and validate diagnostic measures and tests to diagnose or to determine the status of primary diseases before the symptoms will develop. Such steps will attempt to prevent disease progression in individuals and help researchers to determine whether an experimental treatment is or is not effective, and thus either make it more widely available, or attempt the investigation in order to pursue other opportunities or paths.

These are some of the exciting opportunities and challenges, Mr. Chairman. The Council appreciates your support for the NIH, and urges you to consider our request for doubling over 5 years and a 15 percent increase. We realize you have a tough job and many priorities, but thank you for this opportunity. We are willing to take any questions.

[The prepared statement of Mike Miller, M.D., follows:]

[Pages 18 - 27--The official Committee record contains additional material here.]

Mr. Porter. Dr. Miller, thank you, sir, for your excellent statement. Let me say that the American people do intuitively understand the importance of biomedical research, but all of us, all of you, have to somehow get the message out as to what progress has been made, why it is important to human beings. It is not only important to improve lives, it saves health care costs tremendously. It improves the quality of life in many different ways.

Somehow we need to get that message out to every American person, not just the Members of Congress but the whole population at large. All of us have to put our shoulder to that wheel if we are going to get the kinds of increases that we think are necessary for NIH.

I would say one other thing. We can only work with what we are given to work with. It is the budget process that allocates the funds. If we sit and wait until the subcommittee marks up its bill and says, oh, fine, you know, and we don't do anything up to that point, we could well have lost the opportunity to make the kinds of commitments to biomedical research that we need to make.

So the fight is right now with the budget process, and getting the kinds of allocations that allow us to make the kinds of increases that both of us and everyone in this room, I suspect, believe are our goal, and what we think will really help advance the cause of biomedical science and improve the lives of every person on the planet. Thank you, Dr. Miller.

Dr. Miller. Thank you. I couldn't agree with both your points any more strongly. Thank you.

Wednesday, January 28, 1998.

WITNESS

JOHN M. CRAWFORD, D.D.S., Ph.D., AMERICAN ASSOCIATION FOR DENTAL RESEARCH

Mr. Porter. John M. Crawford, D.D.S., Ph.D., Professor of Periodontics, the University of Illinois at Chicago, College of Dentistry, representing the American Association for Dental Research.

The Chair welcomes a fellow Chicagoan.

Dr. Crawford. Thank you very much. Thank you for this opportunity to address the committee.

As you indicated, I am here to represent the American Association for Dental Research and its 5,300 members. I would like to discuss the 1999 budget allocation to the National Institute for Dental Research and the Agency for Health Care Policy and Research.

When you deal with the justification of allocations, you have to look back and you have to look forward. You look back to document the successful and the productive and wise use of funds, and the consequent increase in the health of the American people. I think that the NIDR has very good evidence that it has done this in a very successful way. This evidence we will present in our written testimony, and the Director of NIDR will present more evidence for this in his oral testimony.

However, you have to look forward, and you have to present evidence that there are problems yet to be solved. These problems can be solved with the manpower and technology available. It is this point I would like to discuss briefly today.

I would like to present a scenario for oral health management in the 21st century. I think this will focus on identification of people at risk for oral disease, and there is a lot of evidence that this is not distributed evenly through the population of the U.S. There are people at risk and people relatively immune.

We have already saliva-based tests to predict dental decay activity, and there is interesting recent work which begins to show us that we can predict the activity of gum disease as well. Having identified people at risk, we will then be able to offer them lifetime immunity from these diseases, and again, the National Institute for Dental Research has supported research which clearly shows the ability to produce a safe and effective vaccine for dental caries, and there is interesting work in the animal models for certain diseases, with mice and monkeys, that shows we may be able to offer a safe and effective vaccine for gum disease as well. So there is a scenario for cost-effective health research focusing on at-risk populations.

I would like to take a moment to describe the situation in 1997, using myself as an example. My dentist tells me to clean my teeth 2 minutes with a toothbrush at night, and added to that, 2 minutes with dental floss. That adds up to about 36\1/2\ hours every year, and if I liveto the age of 76, my actuarial limit, I will have spent 6 months cleaning my teeth. Life is too short.

I would like to also indicate that if you are susceptible to gum disease, you have a lifetime of struggle combatting this disease, slowing it down, and trying to arrest it. This is a chronic, disabling disease. The treatment is very

sophisticated, but it is also time-consuming, very costly, and leads to lost productivity hours.

I would like to point out that teeth are the only organs that we frequently discard before the end of our lives. And I would like to point out that periodontal disease is a major health problem in this country. Recent NIDR-sponsored research has shown that 35.7 million Americans have at least mild bone loss. But more surprisingly and more seriously, 13.1 million Americans have moderate to severe bone loss. So this is a public health problem of pandemic proportions.

I would like to envisage in the near future a longer, healthier life, but at the end of that life, we will have our healthy teeth in our mouths.

Mr. Chairman, the American Association for Dental Research supports the ad hoc group's overall recommendation for NIH of $15,695,000,000. More specifically, the American Association for Dental Research supports the request for $240,822,000 for the National Institute for Dental Research.

I would also like to take this opportunity to support the work of the Agency for Health Policy and Research, because we strongly feel that research into health care policy is essential for the oral health of the American people.

I would be happy to attempt to answer any questions that you may have.

[The prepared statement of John Crawford follows:]

[Pages 30 - 35--The official Committee record contains additional material here.]

Mr. Porter. Dr. Crawford, did you say 15.95 billion?

Dr. Crawford. The figure that I quoted was $15,695,000,000.

Mr. Porter. What does that represent?

Dr. Crawford. That represents a 15 percent increase, I believe.

Mr. Porter. Whose figure is that?

Dr. Crawford. The ad hoc group's overall recommendation for NIH.

Mr. Porter. I have already given my sermonette about how we get there, but let's all work together to achieve that.

Dr. Crawford. Yes, indeed.

Mr. Porter. Thank you very much for your good testimony.

Wednesday, January 28, 1998.

WITNESS

DAVID RECKER, M.D., AMERICAN COLLEGE OF RHEUMATOLOGY

Mr. Porter. David Recker, M.D., Member, ACR Government Affairs Committee, representing the American College of Rheumatology.

Dr. Recker. Good morning, Mr. Porter. I am David Recker, M.D. I am a rheumatologist from Auburn, Pennsylvania, and I am here today to testify for the American College of Rheumatology

in support of funding for the National Institutes of Arthritis and Musculoskeletal and Skin Diseases and for the NIH as a whole.

The ACR is a professional organization of rheumatologists. It includes practicing physicians, research scientists, nurses, physical and occupational therapists, and other allied health professionals. We are dedicated to understanding, treating, and hopefully one day curing the more than 100 types of arthritis and related disorders that involve joints, skin, bones, and connective tissue.

These conditions often result in severe disability and sometimes even in death. In just a few years we face the coming of a new millennium. Amid the hoopla and celebration of this event, there is a certain amount of uncertainty and speculation; but future events await us, our children, our children's children. What challenges does our Nation face in defining its existence? Will John Elway, one of the last baby-boomers, continue to be able to play into the 21st century?

What we do know is that in the year 2000, some 20 million American baby-boomers will turn age 50. We also know that this Nation's aging population will be stricken with an ever-growing burden of arthritis unless something is done to halt the progression of these debilitating conditions. A study from the Journal of the American Medical Association revealed that nearly half of all Americans age 60 and above suffer from some form of arthritis.

Studies have shown that no condition impairs the overall quality of life in more older Americans and to a greater extent than does arthritis. Swollen and disfigured joints not only hurt, they significantly hinder effective individuals in their ability to perform even the most basic of daily functions such as bathing, dressing, and eating. I can tell you from my personal clinical experience how vibrant, happy, productive individuals have become dependent, pain-ridden, despondent, and even depressed as these afflictions rob them of their functional capacity and steal from society their irreplaceable productivity.

As I have already mentioned, our ever-aging population means more and more individuals will face the potential ravages of arthritis. Providing care for this growing number of Americans means that the government, private insurers, and indeed society as a whole will bear an ever-increasing economic burden.

While arthritis typically is encountered in older populations, in reality no age is spared from this group of diseases. Disorders such as juvenile rheumatoid arthritis, which can strike children at virtually any age, can lead to lifelong disability, disfigurement and pain. Younger adults are also subject to the pain and suffering imparted by rheumatic diseases. Systemic lupus erythematosus, for example, is typically a disease of young, otherwise healthy women.

Through increased research into the basic pathology and origin of these diseases, as well as through increased investigation into better treatment and management strategies, we can potentially greatly mitigate the costs of these diseases in both personal and economic terms, and we can improve the overall quality of life of afflicted individuals.

I am here on behalf of the ACR to voice support for the appropriations for the NIH as a whole, and more specifically, the ACR joins with the other 200 other organizations who together form the Ad Hoc Group for Medical Research Funding to support a 15 percent NIH-wide increase in biomedical research and training, as indeed a first step to doubling the NIH budget in the next 5 years.

The ACR, along with other members of the Coalition of Professional and Voluntary Groups Concerned with the Programs of NIAMS, endorsed this increase, translated to this specific Institute's budget. This would result in funding NIAMS at approximately $316 million, $40 million more than the current fiscal year.

What can we do with this increased funding? Funded in part by NIAMS, researchers have recently discovered mutations in certain genes which may lead to an overgrowth of synovial tissue. The linings of joints in patients with arthritis have severely thickened synovia, and it is this thick synovia that is felt to be responsible for much of the disease's devastating problems. By further investigating how to control and limit the growth of synovia, we can potentially mitigate some of the ravaging effects of rheumatoid arthritis.

On a more practical matter, again, researchers funded by NIAMS have assessed the medical and economic impact of joint replacement, currently an option for Americans enduring the pain of arthritis. Joint replacement is nevertheless expensive. It costs about $48,000 for a typical hip replacement. The cost for nonsurgical intervention, however, has been shown by these researchers to be $165,000, three times more expensive. This analysis does not even consider the impact of the quality of life.

The cooperative efforts as well, of NIAMS-funded researchers, can investigate questions that will further the mission of the Institute. Through collaboration with the Aging Institute, with the National Institute of Child Health and Human Development, and with NEI and NIRD, we can again further the mission statement.

The ACR certainly commends the leadership demonstrated by this committee, and you particularly, Mr. Porter, in support of the Nation's biomedical research effort. We strongly urge this subcommittee to continue its effort and to support the 15 percent funding in programs of the National Institutes of Health.

Thank you.

[The prepared statement of David Recker, M.D. follows:]

[Pages 39 - 48--The official Committee record contains additional material here.]

Mr. Porter. Dr. Recker, thank you very much.

I have to say, sometimes, often, there is a great deal of frustration for the chair, because there are lots of questions I would like to ask you about what genetic basis for the disease, if any, has been discovered, environmental factors, mental factors, and the like. But I don't have time to ask

those kinds of questions and receive your answers at this point. It is true of almost all of our witnesses, and the difficulty is, we are limited by the time we have, so we have to do the best we can.

But thank you very much for your testimony today. I very much appreciate it. Obviously, we are going to do our very best to meet the goals that you have described for NIH and for NIAMS.

Dr. Recker. We will be happy to answer any questions.

Wednesday, January 28, 1998.

WITNESS

ROBERT O. KELLEY, Ph.D., ASSOCIATION OF AMERICAN MEDICAL COLLEGES

Mr. Porter. Robert O. Kelley, Ph.D., associate vice chancellor for research and executive associate dean of the Graduate College, University of Illinois College of Medicine, representing the Association of American Medical Colleges.

Dr. Kelley.

Dr. Kelley. Thank you, Mr. Porter.

My name is Robert Kelley. The University of Illinois, especially the University of Illinois at Chicago, and the Association of American Medical Colleges thanks the subcommittee for their continued support of the National Institutes of Health and the other programs I will discuss.

In particular, Mr. Chairman, we want to thank you for your leadership on behalf of medical and biomedical research. I will summarize my written statement with the following points.

The Federal investment in medical research, through the NIH, continues to yield a profusion of fundamental and applied knowledge transforming the practice of medicine. In addition to its enormous benefit to the health of the American people, NIH-sponsored research also continues to provide the basis for much of the sustained success of the biotechnology and pharmaceutical industries.

Still, America faces serious health problems, and new threats constantly appear. Congressional support for medical research has produced a wealth of scientific opportunities to answer these challenges. If we are to sustain this momentum and translate the promise of science into improved health for all Americans, we must redouble our national commitment to medical research.

The Association of American Medical Colleges endorses the recommendation of the Ad Hoc Group for Medical Research Funding for a 15 percent increase in the NIH budget as the first step toward the goal of doubling NIH funding over the next 5 years. Science is changing at a breathtaking pace, and we must invest in new technologies, new personnel, and new research infrastructure if we are to take full advantage of this science.

The Association of American Medical Colleges urges the subcommittee to pay particular attention to the needs of the National Center for Research Resources, which provides support for the general clinical research centers and other essential

elements of a vigorous research environment.

The transformation of the health care system to a market-driven, price-competitive structure poses a significant threat to the ability of medical schools and teaching hospitals to maintain an environment for research and innovation. The Association of American Medical Colleges strongly urges the Congress to provide for flexible but accountable institutional support by funding the Biomedical Research Support Grant program, BRSG.

The geographic and specialty maldistributions of physicians in the United States are critical issues facing both the Congress and the Nation. The Association of American Medical Colleges urges the subcommittee to provide additional funding for the National Health Service Corps and the health professions education programs authorized under Titles VII and VIII of the Public Health Service Act, which play a major role in addressing these problems.

The Association of American Medical Colleges thanks the subcommittee for sustaining funding in fiscal year 1997 for the health professions and nursing education programs, and the AAMC joins the Health Professions and Nursing Education Coalition in urging the subcommittee to provide at least $306 million for fiscal year 1999.

The drive to cut health care costs raises concerns about the quality and appropriateness of care and the choices available to consumers. The Agency for Health Care Policy and Research is charged with sponsoring health services research designed to improve the quality of health care, decrease health care costs, and provide access to additional health care services in a rapidly changing marketplace. The Association of American Medical Colleges believes strongly in the value of health services research as this Nation continues to strive to provide high-quality health care for all of its citizens.

The Association of American Medical Colleges endorses the Friends of the Agency for Health Care Policy and Research in their recommendation of a fiscal year 1999 funding level of $175 million for the AHCPR. As you know, it is the major Federal program supporting the widely-recognized need to strengthen our knowledge of and commitment to evidence-based medicine.

Finally, we wish to emphasize the importance of research, training, and health professions programs targeted at the racial and ethnic groups that are underrepresented in medicine and research. Support for these programs is more crucial than ever.

The Association of American Medical Colleges appreciates the continued support of your subcommittee and the support that has given to all the programs cited in my written statement. We take very seriously the charge you just gave to others and look forward to working with you on behalf of those charges.

[The prepared statement of Robert Kelley follows:]

[Pages 51 - 57--The official Committee record contains additional material here.]

Mr. Porter. Dr. Kelley, thank you very much.

Now that my colleague, Congressman Stokes, is here, so that both sides of the aisle are represented, I can ask this question. Does the AAMC have a reaction to what the President said regarding research in his State of the Union Address last night?

Dr. Kelley. We are certainly supportive of biomedical research and the goals it brings, to the benefit of the American people. I think when we represent all of the people and all of our cities, all of our States, I think everything we can do as a people to support the goals of biomedical research we would certainly stand behind.

Mr. Porter. What I understood from the President's remarks, and, Lou, you can correct me if I am wrong, but he said a 50 percent increase in all research, all basic research, over the next 5 years, not the 100 percent increase that our witnesses here have been talking about.

Dr. Kelley. I think the AAMC would certainly stand behind doing as much as we could. We would certainly support the ad hoc group's recommendations and I think the position that you are representing, trying to do as much as we possibly can for NIH and biomedical research.

Mr. Porter. Tell the President and the Committee on the Budget.

Dr. Kelley. We certainly shall. Thank you.

Wednesday, January 28, 1998.

WITNESS

ERIC NEILSON, M.D., AD HOC GROUP FOR MEDICAL RESEARCH FUNDING

Mr. Porter. Eric Neilson, M.D., the C. Mahlon Kline professor of medicine and pediatrics at the University of Pennsylvania School of Medicine, and founding president of the Association of Subspecialty Professors, representing the Ad Hoc Group for Medical Research Funding.

Dr. Neilson. Good morning, Mr. Porter. Thank you.

I am testifying on behalf of the Ad Hoc Group for Medical Research Funding, as the first coalition of nearly 200 organizations representing patient groups, medical scientific societies, academic and research organizations, and industry.

Mr. Chairman, we thank you and the members of the subcommittee for making the National Institutes of Health one of your very highest priorities.

I would like to make the following points to summarize my written statement. As a consequence of the Federal commitment to medical research, an ever expanding base of scientific knowledge about health and diseases is being developed that is revolutionizing both the conduct of the scientific inquiry and the practice of medicine. If we are to sustain this momentum and reap the full benefits of this investment, then the Nation must commit to its plan for significant and sustained funding for the NIH.

We commend the leadership demonstrated by the congressional sponsors of proposals to double the NIH budget over the next 5

years. For fiscal year 1999, the Ad Hoc Group supports a 15 percent increase in NIH funding as the first step towards the goal of doubling the NIH budget over the next 5 years. We believe this increase is justified both by the health needs and research capacity of the Nation. Such a long-term commitment will also stabilize sensible planning through use of those funds.

Congressional support for the NIH over the past 40 years has produced a wealth of opportunities in basic and clinical science that will ultimately alleviate and eliminate many of the health challenges we currently face. In addition, medical research plays an important role in the growth of biotechnology and pharmaceutical industries.

I personally have been supported throughout my career by the NIH. I am now a principal investigator of five NIH grants. I serve on the National Advisory Council for the National Institutes on Diabetes, Digestive and Kidney Diseases.

Permit me to make the following observations on the needs for additional funding that we are recommending. Science is changing at a revolutionary pace. It requires investment in new technologies and a renewed research infrastructure, including people with appropriate skills to meet this new science.

As someone who has trained numerous physician scientists over the last 25 years, I can say that one of the most pressing needs we face in the area of training, particularly for clinical research, is for physician scientists. We need to expand clinical research training opportunities. Additional funds could be used to raise the stipends and to lengthen the training period for clinician scientists to at least 3 years. We have a crisis in the Nation in attracting and retaining new investigators in these areas. Direct attention to this budget item would be most important.

Additional funds could also be used to enhance clinical research infrastructure, including increased support for general clinical research centers. A reinvigorated GCRC program could serve as a focal point for clinical training as well as expand clinical research activities. This would happily avoid a new administrative entity and focus initial efforts towards institutions with established records of clinical research excellence.

At the same time, of course, we must also sustain and enhance our basic research, including increased support for current researchers, as well as promoting opportunities for new investigators in those areas of biomedical science that have been underfunded.

We particularly need to enhance the institutional research capacity, including renovation of outdated facilities, creating new approaches to support animal facilities, providing state-of-the-art instrumentation and other research equipment, promoting informational and computer technology, and substantially increasing the funding for research support programs under the National Center for Research Resources.

Finally, continued progress in medical research depends on the advancement in related fields of science, including chemistry, physics, mathematics, and engineering. We urge the administration and the Congress to consider the breadth of this Nation's research efforts as interdependent and fund them

accordingly.

In closing, we recognize the difficulty of achieving the goal we have articulated under the Center spending caps. A national commitment to doubling the NIH budget over the next 5 years will necessitate additional resources to sustain the growth of the coming years. The Ad Hoc Group urges the Congress to explore carefully all options to identify new resources. We feel that leveraging other entities and other opportunities is very important to this process in bringing other individuals into the discussion.

We stand ready to work with the supporters of medical research on Capitol Hill to achieve this goal, beginning with fiscal year 1999 and beyond, and thank you very much for your time and attention. I am happy to answer any questions relating to my comments.

[The prepared statement of Eric Neilson, M.D., follows:]

[Pages 61 - 69--The official Committee record contains additional material here.]

Mr. Porter. Dr. Neilson and Dr. Kelley, I want to explain that I was encouraged by what the President had to say in his speech last night. He talked, Dr. Neilson, not only about biomedical research, but all basic research.

Dr. Neilson. Yes.

Mr. Porter. For the reasons you have stated, but also for the strategic political reason that I do not think we can set one type of research against another in our Federal budget, they have to go relatively hand in hand.

I think that the President's remarks were very encouraging, and all of you probably realize--at least this is the way I think about it--that when the President of the United States gives support for a figure for NIH that is an increase of about 8.2 or 3 percent, that becomes, to us, a floor from which we perhaps, if we get the resources, can work and even do better.

So I feel very encouraged by what the President had to say. I said that publicly, both to the electronic and print media, and I think it indicates a new commitment from the White House to put this at a very high priority.

Having said that, all of us have to realize that the President's budget has about $100 million of new revenues that very possibly could never materialize. There are many in the Congress who are very opposed to any kind of new revenues, even tobacco taxes, which I think are very justified, and whether we can get the revenue increases to support the spending increases is at this point, I think, very problematical.

I was very encouraged by what the President had to say, and I have to say, Lou, I said that to everybody who asked and, in fact, some who didn't ask.

So thank you, Dr. Neilson, for your very good testimony. We appreciate it, and we are going to do our very best to work very closely with the Ad Hoc Committee and push very hard to put biomedical research at a high priority within all of the programs of the administration.

Thank you.

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Wednesday, January 28, 1998.

WITNESS

ROBERT R. RICH, M.D., THE AMERICAN ASSOCIATION OF IMMUNOLOGISTS

Mr. Porter. Robert R. Rich, M.D., vice president and dean of research, Baylor College of Medicine, Houston, and chairman of the Committee on Public Affairs, representing the American Association of Immunologists.

Dr. Rich, welcome.

Dr. Rich. Thank you very much, Mr. Chairman. It is a pleasure to have the opportunity to represent the 6,000 scientists of the American Association of Immunologists.

I would like to begin this morning by simply saying how much we are indebted to you and to this committee for the extraordinary support you have given to the biomedical research efforts over the past 3 years.

Indeed, at a time when you have been mandated to cut more than $50 billion from the allocations to this subcommittee, you have managed to provide important increases in the allocation to NIH in every year, and we are very, very grateful for that.

We are also very grateful to you and to Mr. Miller for your attention to an issue that we called to your attention several years ago relating to the regulatory burdens that we face as we try to make the research that we do with your appropriated dollars increasingly more efficient. We understand that this is going forward now, as you have called for a private sector study from NIH to look into this issue. We are anxious to work with that study in any way we can tobe helpful.

Mr. Porter. Dr. Rich, I want to say that Dan Miller has taken the lead on that and done, I think, a very, very fine job of putting that issue before us and pushing hard to get it resolved.

Dr. Rich. We are very grateful for that, and we very much appreciate that.

What I would like to talk about today are two issues. The first is a problem and the second is an opportunity.

The problem we have already heard about from the AAMC. That is, with the increasing competitive managed care environment, we find that our academic medical centers really can no longer afford to support the research faculty which is so vital to the activities of NIH.

Interestingly, as they indicated to you, a solution already exists in the law; that is, the Biomedical Research Support Grant program, or BRSG. Indeed, in 1990, NIH said, this program recognizes the need to support new investigators, to explore new and unorthodox research ideas and techniques, to respond promptly to opportunities that develop in the course of active and diverse research programs, and to provide central shared resources.

For the 27 years of its funding, the BRSG program received a median of 2.4 percent of the research project grant budget that was given to the institutions. This year, that would equate to approximately $186 million. However, in 1992 funding

for the BRSG program was discontinued over concerns regarding its accountability.

Mr. Chairman, I submit that that is a problem we can fix. Last year, I advocated that we reestablish the BRSG program with full peer review and accountability. The subcommittee agreed with this proposition, requesting that the NIH study the feasibility of reestablishing a revised Biomedical Research Support Grant program.

I come before you today requesting an appropriation for a new BRSG program on an experimental basis for a 3-year trial period. I would suggest an appropriation of $155 million in the first year, which would be about 2 percent of the research program grants budget.

I would further suggest that such a program be established based on three fundamental principles: One, that the monies be used for currently defined purposes; second, that the funding be distributed according to a process of strict institutional peer review; and, third, that the NIH be charged to develop a mechanism for accountability. I provided details of each of these principles in my written testimony.

This brings me, then, in closing, to the opportunity. This year we celebrate the 20th anniversary of Edward Jenner's discovery of the principles of vaccination. Within the past 50 years, we have seen many of the historical scourges of mankind essentially disappear. Indeed, the target of Jenner's work, smallpox, has been eradicated from the Earth.

Yet, I need not remind the members of this subcommittee that we still face formidable threats. We all heard about the bird flu from Hong Kong in very recent weeks. And recognizing that the only way we are going to really confront the problem of HIV and defeat it is to develop an effective vaccine, the NIH last year established a vaccine research center on the campus in Bethesda. The AAI supports this initiative of vaccine development but would like to make some suggestions to you in terms of how it might be modified, because we believe that, first of all, the time is now to extend it beyond the NIH campus and to extend its focus beyond HIV.

Indeed, we recognize that there are many important scourges of an infectious nature that remain before us. Perhaps more excitingly, however, is the idea that the principles behind vaccination can now, with new scientific opportunities, be turned to diseases of a noninfectious nature. We are very excited, at AAI, about the possibility that the human immune system might be programmed to attack a variety of diseases before they develop.

What kind of diseases am I thinking about? I am particularly attracted to the notion of autoimmunity and cancers. That is right, Mr. Chairman. As an immunologist, I can tell you that we can look to the day when we might be able to vaccinate our children against lupus, multiple sclerosis, diabetes, and rheumatoid arthritis, much as we vaccinate them against measles and polio today.

Thank you again very much for the subcommittee's support. We appreciate the opportunity to testify before you.

[The prepared statement of Robert Rich, M.D., follows:]

[Pages 73 - 81--The official Committee record contains additional material here.]

Mr. Porter. Dr. Rich, thank you very much.

I have one quick question. Is the BRSG program going to appear in the President's budget? In other words, is he suggesting that we provide this funding, do you know?

Dr. Rich. We have not seen that. I would be surprised if we see a line item appropriation. I think that--but we have not seen the details of the President's budget.

Mr. Porter. Thank you very much. We appreciate your testimony.

Wednesday, January 28, 1998.

WITNESSES

CLAUDIA E. MILLER, Ph.D., M.T., AMERICAN SOCIETY OF CLINICAL PATHOLOGISTS

SARA BROWMAN, JOHN EDWARD PORTER SCHOLAR

Mr. Porter. Dr. Claudia Miller, director of Medical Technology Programs and chair of Allied Health at National Lewis University in Evanston, Illinois--that is my hometown--accompanied by Sara Browman, the Porter Scholar.

Hi, Sara.

Welcome, Dr. Miller.

Dr. Miller. Good morning, Chairman Porter, Mr. Stokes.

I represent the American Society of Clinical Pathologists. I have served on their Educators Committee, and I have been a regional representative and recruiter.

The American Society of Clinical Pathologists, the ASCP, is a medical not-for-profit society which has as its goal scientific and educational purposes. It has 75,000 members, and they include not only board-certified pathologists but other physicians, Ph.D. scientists, and board-certified technologists and technicians.

The allied health professions serve 60 percent of the health care work force today, and we serve in all different tiers, from hospitals to health care, extended health care, skilled nursing, and even physicians' offices.

The Allied Health Grant program, which is under section 767, Title VII, of the Public Health Service Act, has been very effective in dealing with allied health needs, but more resources are needed simply because we need more allied health professionals to serve the United States population. Shortages are evident by vacancy rates, and I will give you some examples of those.

In laboratory medicine, we have in histotechnology an 11.7 percent shortage. These are the people who prepare tissues for examination. In cytotechnology supervisors, the people who look at cells to assess the status of cancer malignancies, there is a 14.1 percent.

Some people argue that it is not the responsibility of the Federal Government to aid allied health programs. We agree. The

private sector does have to take responsibility. The ASCP does this by offering 50 scholarships annually to medical technology, medical laboratory technicians, histotechnology technicians, and also cytotechnology students.

I have here beside me Sara Browman, who is the 1998 recipient of the scholarship named in your honor, Mr. Porter, because of your support to allied health.

But there is a difference. The ASCP gives monies to students like Sara, but the Allied Health Project Grant program gives money to schools so that students like Sara will have the opportunity to receive an education and be able to work in allied health.

We have very many success stories. One is at the University of Nebraska Medical Technology Program, where, with the third $358,000 they received in 1992, they were able to start a world health program. Fifty-three medical technology students graduated, and 94 percent remained in the rural area to serve people in clinical laboratory medicine. They are now self-sufficient, and many of their students from the regular on-campus program are actually seeking employment in rural areas.

The University of Maryland, using a grant that they received in 1991, has addressed the problem of minority recruitment and retention. I am very happy to tell you that in 1996 the Medical Technology Program had 52 percent minority students, and they have a 95 percent retention rate. This is at a majority institution, and the retention rate is one of the highest in the Nation.

The monies from Allied Health Project Grants actually are used to help establish critical need programs. Project outcomes are tracked; information is shared with other programs so that they are able to go out and start programs that are needed using limited resources.

Keeping in mind that these programs have been so successful and that we so desperately need more allied health professionals, we urge you to consider funding the Allied Health Projects Grant program for fiscal year 1999 for $10 million and the Health Professions Training program for $306 million.

Thank you for your consideration.

[The prepared statement of Claudia Miller follows:]

[Pages 84 - 91--The official Committee record contains additional material here.]

Mr. Porter. Thank you very much, Dr. Miller.

Sara, your hometown is what?

Ms. Browman. Rockford, Illinois.

Mr. Porter. Rockford, Illinois. My wife's mother lives in Rockford, Illinois, so I am there frequently. We welcome you. I am very honored that you are the Porter scholar.

There are a number of scholarships that you have named for a number of different individuals at National Lewis; is that correct?

Dr. Miller. We have a lot of scholarships, yes, especially Mr. Lewis, who gave us all the money for our university.

Mr. Porter. Especially Mr. Lewis. That makes good sense.

Well, Sara, we appreciate your joining Dr. Miller this morning, and we wish you well in your career. We are honored that there is a scholarship in my name and that you are the scholar. Thank you both for being here.

Mr. Stokes.

Mr. Stokes. Mr. Chairman, I would just like to take a moment and thank Dr. Miller for sharing with us the success of her minority recruitment program. This is welcome news, particularly at a time when, because of the assault upon affirmative action, we are finding now that throughout the Nation there has been a considerable drop in even theapplications by minority students because of the fear and the actual threat of not being accepted, and so forth.

The fact that you are having this type of success with it is very encouraging, and I think it speaks loud and clear to other institutions, particularly majority institutions, as you have cited, of the absolute need to do something more in this area. I really appreciate your sharing this with us.

Dr. Miller. Thank you, Mr. Stokes.

I think that the success of the program at the University of Maryland is because of early intervention. They start in elementary school, track them through middle school, and then continue on until they receive their bachelor's degree.

Mr. Stokes. I may want to get a chance to talk with you a little further about your program and get some information. Maybe we can help some of the other institutions in this respect.

Dr. Miller. That would be wonderful. Thank you very much.

Mr. Stokes. Thank you.

Mr. Porter. Thank you, Dr. Miller and Ms. Browman.

Wednesday, January 28, 1998.

WITNESS

JOHN F. NEYLAN, M.D., AMERICAN SOCIETY OF TRANSPLANT PHYSICIANS

Mr. Porter. Dr. John F. Neylan, President-Elect of the American Society of Transplant Physicians, testifying on behalf of the Society.

Dr. Neylan. Mr. Chairman and members of the subcommittee, thank you for the opportunity to present testimony on behalf of the American Society of Transplant Physicians. I am John Neylan, Medical Director of Kidney Transplantation at Emory University and President-Elect of the American Society of Transplant Physicians.

The ASTP, which receives no government support, has over 1,100 physicians, surgeons, and scientists actively engaged in the research and practice of transplantation medicine and immunobiology, and represents the largest and broadest number of transplant professionals in the United States.

Over the past 30 years, transplantation of solid organs has moved from experimental to accepted therapy, with over 20,000 performed in 1997 in the U.S. The success of this procedure has improved greatly, and now almost all solid organ transplant recipients have an 83 to 97 percent survival rate at 1 year.

Much of this success can be attributed to the basic and clinical research that has been funded by previous NIH appropriations. Our better understanding of the body's response to foreign proteins has led to countless other breakthroughs in all areas of medical science.

However, we still have a long road ahead. During the next hour, four new names will join those 56,793 individuals in this country waiting for a solid organ transplant. By the time I get home to Atlanta this evening, 10 individuals will have died because the wait for a transplant was just too long. For those fortunate individuals who received this gift of life, the long term still holds potential pitfalls and obstruction for poorly understood mechanisms of immune destruction as they exact a relentless attrition.

But, Mr. Chairman, with increased funding for research, there is hope. Research is central to all that occurs in the transplantation process. The ASTP believes that we are on the threshold of many important scientific breakthroughs in the areas of immunology and cell biology.

We are on the threshold of developing safer and more effective means of immunosuppression to combat the complex pathways of acute and chronic rejection. With further insights, we may see the dawn of conditioning regimens that may one day lead to indefinite and drug-free immunologic tolerance. In parallel, we may devise means to overcome the daunting immunologic hurdles of xenotransplantation, the transplantation of a potentially limitless supply of animal organs.

Finally, advances in developmental cellular biology may one day lead to reconstruction of human tissues and organs damaged by disease, and restore these to health and normal function. None of these goals are possible without strong support for research.

Because of this, the ASTP strongly urges the subcommittee to continue its leadership in the area of biomedical research and provide a 15 percent increase in funding for the NIH for fiscal year 1999. By continuing to increase the level of funding, this subcommittee will achieve the goal of doubling the NIH budget in 5 years, a goal supported by the ASTP, and as you have just heard, by the societies who are members of the Ad Hoc Coalition for Biomedical Research.

With this level of support, this subcommittee and the Congress as a whole will have the personal satisfaction of knowing that they are responsible for expanding the general transplantation research authority at the NIH, and in turn will be providing new hope to the countless citizens of this country who may one day benefit by these efforts.

Thank you, Mr. Chairman and all the members of your committee for allowing me to present the views of the ASTP and the transplant community.

[The prepared statement of John Neylan, M.D., follows:]

[Pages 95 - 102--The official Committee record contains additional material here.]

Mr. Porter. Dr. Neylan, thank you very much for your

excellent statement. You kind of give us a hope for the future that--I remember talking to a physician about 10 years ago saying that we are on the edge of being able to replace worn-out or defective organs, and now you are telling me that that is increasingly coming true, and all we need is a stronger commitment to research to make it happen even more rapidly.

So we appreciate very much your testimony this morning. Thank you for being with us.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness]

Wednesday, January 28, 1998.

WITNESS

DR. HARRY S. JACOB, THE AMERICAN SOCIETY OF HEMATOLOGY

Mr. Porter. Dr. Harry S. Jacob, President-Elect of the American Society of Hematology, representing that society.

Dr. Jacob.

Dr. Jacob. Good morning.

Thank you, Mr. Chairman, for letting me meet with you today. I am a professor of medicine at the University of Minnesota and President-Elect of the American Society of Hematology. Our society has over 8,000 active members, and probably hosts approximately 15,000 attendees at our annual scientific meeting. Our membership includes physicians who treat blood diseases and scientists who study the causes of those diseases.

I would like to begin by thanking you for your sustained support of biomedical research, and by endorsing your vision that this support should be broad and flexible.

I shall take the next few minutes to discuss how your additional support might help us in our mission to improve patient care. I shall in this forum use two relevant examples: bone marrow transplantation and gene therapy. I will provide other examples in my written testimony.

Bone marrow transplantation is an increasingly-utilized and lifesaving procedure that was invented by hematologists. In fact, a member of our society, Don Thomas, recently won the Nobel Prize for his pioneering work in this area. At present, the procedure is used to treat patients with various forms of leukemia, as well as bone marrow failure and rare immunodeficiency syndromes which affect particularly children.

Also, promising new uses of the technique have been reported in hematologic patients with sickle cell anemia and Cooley's anemia. There is also growing excitement about its ability to treat nonhematologic diseases like systemic lupus, rheumatoid arthritis and multiple sclerosis.

The major limitation in bone marrow transplantation is that the procedure works best when patients have a genetically compatible brother or sister. Unfortunately, this favorable situation occurs for only 1 in 4 transplant candidates. Others must settle for riskier transplantations from genetically

matched but unrelated donors, or they may have to forego the procedure altogether. Research is needed to understand how to safely transplant partially matched marrow so that this lifesaving procedure may become available to many more patients.

The second example I would like to discuss is in the area of gene therapy, an area of great interest to all biomedical scientists and physicians. The bone marrow is the usual source of cells for gene therapy. Sickle cell disease, many forms of immunodeficiency, and severe bleeding disorders, like hemophilia, are just a few examples that may be amenable to correction with gene therapy.

The application of this technology is impeded, however, as we are still unable to regularly transfer genes into cells at high enough levels and maintain these genes in active form for prolonged periods of time. Fundamental research is needed to improve our understanding of these processes so this technology may become more useful. This will require a larger commitment to basic research, but successful resolution will reap enormous rewards for diverse patients. I predict that the appropriate use of gene transfer techniques will soon astonish even the most cynical, and remarkably improve our Nation's health.

The American Society of Hematology is committed to research because our members constantly confront the limits of medical knowledge as they treat catastrophic diseases of the blood, like leukemias, lymphomas, and sickle cell anemia. Our members are also clear that what they are able to do for their patients is based almost entirely on the fruits of previous research.

One example of our commitment to research is that we allocate a major fraction of our limited resources to the funding of fellowships and grants to young investigators. Our members know, however, that our site, although well-intentioned, can merely seed and supplement what the Federal Government sustains through its funding of research.

We ask that you continue your commitment to all high-priority research by supporting a 15 percent increase in NIH funding for fiscal year 1999, as recommended by the Ad Hoc Group for Medical Research Funding. We fervently hope that you can build on the administration's proposal and develop a method to double the NIH budget in the next 5 years.

On behalf of our society, thank you for your attention today, and for your very hard work and generous past support.

[The prepared statement of Dr. Harry Jacob follows:]

[Pages 105 - 115--The official Committee record contains additional material here.]

Mr. Porter. Dr. Jacob, thank you for your testimony. I am sure you are aware that whenever the subject of bone marrow transplantation arises, there is always at the table in this subcommittee a champion of that cause, and that is Bill Young of Florida. So we put that at a high priority, not only because of its intrinsic need and value, but because Bill was always there telling us we should. So we appreciate very much your testimony this morning. Thank you for coming down to be with

us.

Dr. Jacob. It is a pleasure to meet you finally.

Mr. Porter. We have now completed 10 of the 20 scheduled witnesses this morning. We have done so in approximately an hour. We are going to stand in recess for about 3 minutes, and then attempt to allow the next 10 witnesses the remaining hour. We stand in recess briefly.

[Recess.]

Wednesday, January 28, 1998.

WITNESS

DR. WADI N. SUKI, THE AMERIAN SOCIETY OF NEPHROLOGY

Mr. Porter. The subcommittee will come to order. Our next witness is Dr. Wadi N. Suki, President of the American Society of Nephrology, representing that society.

Dr. Suki. Thank you, Chairman Porter, for allowing me the opportunity to speak before your committee this morning.

I am Wadi Suki. I am a professor of medicine and Chief of Nephrology at Baylor College of Medicine in Houston. I am the current President of the American Society of Nephrology.

Our society is the largest professional society in nephrology. We have a membership of some 6,500 clinicians and scientists dealing with function and disorders of the kidney, and dedicated to curing kidney disease. We are here to speak in support of the increased funding of the National Institutes of Health in general, and the National Institute of Diabetes, Digestive and Kidney Diseases, in specific.

Mr. Chairman, this country has a very heavy burden in terms of patients with kidney disease. In our country today there are approximately 300,000 patients who suffer from end-stage renal disease. Their numbers increase by approximately 70,000 new patients every year.

The cost of taking care of these patients is staggering. The total cost approximates some $13 billion, and these patients are increasing, had been increasing at the rate of some 9 percent per year. Hypothetically, due to some of the advances in research, the rate of growth seems to be slowing down, but in the last 3 years has been on the order of about 7 percent per year. At this rate, we anticipate in the next 10 or 15 years there will be something between 600,000 and 900,000 patients with kidney failure in this country.

The major causes of kidney failure are diabetes and high blood pressure. These two disorders affect disproportionately some of the minority groups in our country, particularly Hispanics and African-Americans. The incidence of kidney failure in the African-American is 5 or 6 times that in the white American. The incidence of end stage kidney failure in the Hispanic American is 2 to 3 times that in the white American. So high blood pressure and diabetes represent major concerns for our society and our membership.

In spite of the huge cost to our Nation for treating patients with end stage renal disease, the expenditure on research on kidney disease is only about 2 percent of the total cost. We think that increased spending on research in this area

will bear important fruit and hopefully increase the quality of life, save lives, and hopefully in the end save our country money as well.

Now, major advances have been made in research in kidney disease in the past several years. Experiments in Dr. Brenner's laboratory in Boston in rats have led to innovations of treatment that now has been shown to reduce the development of kidney failure in diabetes by 50 percent. This is estimated to save this country something on the order of $2.6 billion in the next 5 years. This is a testimony to how good an investment in basic research is, in that it would eventually bear fruit at the clinical level.

There have been very many other advances in recent years. The gene for cystic kidney disease and a variety of other genetic and familiar diseases have been cloned and the defects identified. It is our hope that better understanding of the functions of all of these genes will culminate in cure and prevention.

There are a lot of other studies that demonstrate exciting new findings about arresting experimental nephritis in experimental animals. These advances are about to be tried in human beings, so there is a lot of promise for new breakthroughs and new advances.

There have been many advances. When we look back to when I started in nephrology back around 1965 and where we are today, some 30 years later, major advances have been made. Dialysis and transplantation were dreams. Now they are realities. Unfortunately, as you have heard from my colleague, Dr. John Neylan, neither treatment, dialysis, nor transplantation is currently perfect. Many more advances need to be made and much more research needs to be made.

[The prepared statement of Wadi Suki, M.D., follows:]

[Pages 118 - 124--The official Committee record contains additional material here.]

Mr. Porter. Dr. Suki, our time is up. Let me say two things. First, and I say this often, but I want to emphasize it; none of us up here consider these matters in a vacuum. My wife has diabetes, so I know the dangers of that disease and how it affects the population of our country and the whole world.

Secondly, I recently have been shown some home dialysis units that promise, they tell me, to vastly reduce the cost, which is a major cost in your field. Do you have anything to tell us about that technology and whether it is as promising as I have been led to believe?

Dr. Suki. Yes. Indeed, dialysis in the home is now feasible and has been for some time. It is practiced in most large centers and in many smaller ones, as well. Somewhere between 12 and 15 percent of patients on dialysis actually do undergo dialysis in the home, and dialysis is being perfected, but I think the point that I have tried to make earlier is that dialysis does not replace the normal kidney, and therefore, our task should be to try to prevent kidney disease.

Mr. Porter. Absolutely. My understanding from the people that I talked to is that if this could be very broadly adopted, that it would save a great deal in terms of health care costs and, in a sense, free up dollars that could be spent for research in finding a way to prevent or cure the disease.

Dr. Suki. Very importantly, it could save a great deal in terms of personal hardship. Patients on dialysis have to travel to a dialysis facility 3 times a week, which is a considerable hardship and cost.

Mr. Porter. Thank you very much for your testimony, Dr. Suki.

Dr. Suki. Thank you for allowing me to be here and for your support of biomedical research.

Wednesday, January 28, 1998.

WITNESS

JOSHUA M. JAVITS, ALS ASSOCIATION

Mr. Porter. Joshua M. Javits, a member of the board of trustees representing the ALS Association.

Mr. Javits, it is nice to see you again. Thank you for joining us.

Mr. Javits. Thank you very much.

Mr. Chairman and members of the committee, thank you for the opportunity to testify before the committee on behalf of the Amyotrophic Lateral Sclerosis Association and the 30,000 Americans afflicted with ALS, most commonly known as Lou Gehrig's disease.

Speaking for myself and ALS, I would like to express my deep appreciation to you, Mr. Chairman, and the members of your subcommittee who over recent years have provided strong leadership and support for the research projects on ALS being undertaken by the NIH and the NINDS. I would also like to offer support for congressional efforts to double NIH's research funding over the next 5 years. As we all understand, a dollar spent on the disease today saves many lives and many dollars over the years to come.

We pledge to work with you, Mr. Chairman, and your colleagues on that crucial initiative. As you know, for the last 6 years the subcommittee has included language in the Labor-HHS appropriations bill that is specifically aimed at increasing the funding for ALS research at NIH within the existing NINDS budget. All of us associated with ALS are appreciative for these efforts and we look forward to working with the subcommittee this year and in the years to come until ALS is eliminated.

Mr. Chairman, I am a son of the late Jacob Javits who proudly served this country for 24 years as a Senator from the State of New York and as a Member of the House of Representatives for 8 years. I stress this point because my father died in 1986 after a valiant struggle with ALS, a degenerative and always fatal disease. While in Washington and later in private life, my father maintained an amazing schedule of practicing law and giving speeches and writing articles

despite his diagnosis with ALS. As the disease progressed he required life support, including a respirator and a wheelchair, and eventually becoming virtually paralyzed.

ALS has also claimed the lives of other notables, and took the name of the baseball great, Lou Gehrig, as well as actor David Niven, jazz great Charles Mingus, boxer Ezra Charles, and former Vice President Henry Wallace, and the developer James Rouse.

I serve as a member of the board of trustees of ALS. And ALS, to be specific, is a progressively degenerative neuromuscular disease that attacks the nerve cells and pathways in the brain and spinal cord. Motor neurons, among the largest of all nerve cells, reach from the brain to the spinal cord and from the spinal cord to the muscles throughout the body. When these motor neurons die, as with ALS, the ability of the brain to start and control muscle movement dies with them. The voluntary muscle action is affected and patients become immobilized, eventually leaving the person unable to speak or to eat or to breathe. Yet throughout the degeneration the mind remains completely intact.

ALS was first identified in 1869, but only recently have there been real discoveries that significantly advance the medical and scientific community's understanding of the disease, which underscores our belief that a cause and a cure can be found. To date there are no known causes, it is not known what the cause is, nor is there a cure for those afflicted with ALS. The majority of people diagnosed live only 2 to 5 years. Over 5,000 new cases are diagnosed each year.

ALS knows no boundaries and can strike anyone, regardless of age, race, color, or geographic origin. It is not a rare disease. It is projected that about 300,000 Americans alive and well today will ultimately die from ALS, more than die from Huntington's disease or multiple sclerosis.

Mr. Chairman, I want to mention something we are very proud of. Last year, with the inspired leadership of the late Congressman Walter Capps and Chairman Ben Gilman, H.R.2009, the Amyotrophic Lateral Sclerosis Research and Treatment Act of 1997, was introduced in the House.

This bill was the first bill Congressman Capps introduced while in the House and we are deeply honored by that fact. We are appreciative to Chairman Gilman for carrying forward the legislation in the wake of Congressman Capps' tragic death. The bill would allow Medicare to cover the cost of drugs used to treat ALS and would waive the 24-month waiting period for disabled persons to be covered by Medicare.

The last point is especially critical for ALS patients, who on average do not live more than 2 to 3 years after they become disabled. We believe that Congress, out of a sense of fairness and sound public policy, should look favorably on this legislation. To date 61 of your colleagues have cosponsored H.R. 2009 and we are hopeful that this number will continue to grow.

In the area of research, a major portion of ALS Association's annual budget is committed to fund ALS-specific research. The Association's grant program follows the format and rating procedures established by NIH. The Association, in the last 24 months, has funded over $4.7 million in funding. I

would point out that the Association's research effort amounts to about 30 percent in addition to what NIH puts into ALS research.

Mr. Chairman and members of the committee, please accept our sincere appreciation for all the support you have provided for those afflicted with ALS and their families, the 30,000 people afflicted with ALS. We strongly urge Congress to continue the subcommittee's commitment to long-term medical research and to provide the funds necessary for NIH to carry out the mission. Thank you very much.

[The prepared statement of Joshua Javits follows:]

[Pages 128 - 138--The official Committee record contains additional material here.]

Mr. Porter. Mr. Javits, thank you for again appearing before our subcommittee. You have been a tireless advocate for preventing and controlling this terrible disease, and your father was a man who very clearly made a difference in this world. I think you are making a difference as well, and we very much appreciate your strong advocacy in bringing the dangers and scourge of this disease to our attention. Thank you for being with us.

Mr. Javits. Thank you for your very kind words, Mr. Chairman.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Wednesday, January 28, 1998.

WITNESS

EDWARD L. SNYDER, M.D., AMERICAN ASSOCIATION OF BLOOD BANKS

Mr. Porter. Edward L. Snyder, M.D., Director of the Blood Bank at Yale Medical School and Yale-New Haven Hospital in New Haven, Connecticut, and President of the AABB, representing the American Association of Blood Banks.

Dr. Snyder.

Dr. Snyder. Thank you. Mr. Chairman and members of the subcommittee, my name is Ed Snyder. I am Director of the Blood Bank at Yale, and the Yale-New Haven Hospital in Connecticut. I am testifying today as President of the American Association of Blood Banks in support of increased funding for NIH and NHLBI.

The AABB is a professional society for 8,500 individuals involved in blood banking and transfusion. We represent 2,200 institutional members, including community and Red Cross blood centers, and hospital blood banks that collect, process, and transfuse blood. Our members are responsible for virtually collecting all of the blood in the United States, and more than 80 percent of the blood transfused.

Throughout its 50-year history, the AABB's highest priority

has been to maintain and enhance the safety of the blood supply. NHLBI is currently sponsoring several important transfusion medicine projects. There are, however, important opportunities in this field that require additional investigation to assure the safest possible blood supply.

I would like to emphasize five of these. First is detection of transfusion-transmitted disease. Despite the great progress that has been made in selection of donors who are at low risk for disease transmission and the use of and improvements to tests to eliminate infected donors, prevention of AIDS and other transfusion infections remains a top priority of transfusion researchers and all recipients of blood.

Each improvement to testing has led to a decrease in the window period, the period of time between infection with a viral disease and the ability to detect the virus by a screening. The risk of acquiring viral disease through transfusion is lower than ever, yet worldwide travel and demographics could spread new viruses, bacteria, and parasites into the U.S. blood supply. I call your attention to the concern about the spread of CJK or mad cow disease into the blood supply in the United Kingdom. Prevention of transfusion-transmitted disease remains a priority of transfusion research.

Secondly is the role of biologic response modifiers in transfusion reactions. Studies have identified several substances released by human cells which play a role in changing the patient's response to transfusion. These adverse responses, known as transfusion reactions, range from fever and chills to severe allergic reaction, shock, and even death. Studies on the role of these chemicals and adverse reactions to transfusion and research into how to modify and control them is now necessary.

Third is the immunology of transfusion. Even though blood transfusion is a lifesaving therapy, transfused components are still recognized as a foreign substance by the human body. Blood transfusion can produce adverse changes in the body's immune system. This includes decreasing the natural defense of the patient for their fight againstbacterial infection, or by decreasing their ability to prevent cancer recurrence. Lifesaving transfused blood may thus actually promote disease. Bone marrow transplant patients, cancer patients, and other immunosuppressed recipients are all at risk for immunologic complications. Fundamental basic research is needed to gain knowledge on how to combat these aspects of transfusion.

Fourth is stem cell research. The AABB is pleased that NHLBI is funding a 5-year study of transplanting stem cells collected from cord blood. Stem cells may become the ultimate vehicle for curing diseases through gene therapy. This initiative, however, poses new questions, and we support additional research in this area.

Lastly, transfusion medicine, research training, and its clinical infrastructure needs further evaluation. Our infrastructure is currently nonexistent. We support development of linked centers of transfusion excellence for research and training. Such centers could provide a critical mass of resources needed to accomplish NHLBI-sponsored research in transfusion medicine.

The American Association of Blood Banks endorses a 15

percent increase in NIH funding for fiscal year 1999 as a first step towards doubling the goal of NIH--doubling the NIH budget over the next 5 years. This recommendation is consistent with congressional support for doubling the amount authorized for basic science and medical research for a number of research agencies, including NIH. This level of funding would also sustain the rate of growth NIH has experienced in the past decade.

Mr. Chairman and subcommittee members, on behalf of the many NHLBI-funded transfusion scientists, thousands of health care professionals, and millions of transfusion recipients, we appreciate the opportunity to discuss Federal support for research and transfusion medicine before the subcommittee. Thank you.

[The prepared statement of Edward Snyder, M.D., follows:]

[Pages 141 - 155--The official Committee record contains additional material here.]

Mr. Porter. Dr. Snyder, can I ask a question? The best way to avoid the transmission of diseases through transfusion is for an individual to have their own blood preserved; is that not correct?

Dr. Snyder. The best way to avoid it is to avoid the transfusion.

Mr. Porter. But if you have to have one, have your own blood supply?

Dr. Snyder. You are absolutely right.

Mr. Porter. How long does blood last if someone were to provide their own blood in sufficient quantity? How long could you keep it?

Dr. Snyder. In the liquid state, it can be stored up to 42 days. Frozen, it can be stored up to 10 years.

Mr. Porter. Ten years?

Dr. Snyder. Ten years, frozen.

Mr. Porter. In the frozen state, is it usable in most cases of transfusion?

Dr. Snyder. Yes. The red cells you can freeze. It is a fairly complex issue. If you need platelets which help blood clotting, that cannot be frozen in most cases. It can in some special situations. Plasma can be frozen for up to a year. Red cells can be frozen for 10 years.

Mr. Porter. Are they the most significant in transfusions?

Dr. Snyder. It depends on the illness. If someone has cancer, they may need platelets more than red cells. There is no easy answer.

Mr. Porter. If you could, by law, require people to put aside at a certain age so much of their own blood, that might help a great deal in providing blood for transfusions if they need them, and also to prevent the transmission of diseases through transfusions; correct?

Dr. Snyder. The Association certainly recommends that people donate their own blood for their own use wherever possible, and also those who are healthy enough and pass the required screening tests, donate for the general blood supply.

We don't have enough blood donors to keep the Nation's blood needs kept going.

Mr. Porter. Sometimes I think that people just need to be encouraged to do things that they would naturally want to do but don't have enough push to do it. I have also thought if we could simply tell people that when they reach Medicare eligibility, they have to make a decision. They don't have to do it, but they have to make a decision whether they want to leave a living will or not. They have to make a conscious choice as to whether they want heroic measures applied if they become what a doctor would determine as terminally ill.

I think most people would do that without any problem. I don't think they would have any problem with it. Some would decide they don't want to make a living will and would want the procedures, but most I think would say, no, not at that point. We will trust medical judgment and allow them to make the decision for us.

It seems to me that maybe perhaps if at the same time we said, wouldn't it be a good idea to put aside some of your own blood if it is needed, we might accomplish a great deal in a very practical way, without any kind of intrusion on people's rights.

Dr. Snyder. Certainly using such blood for that same individual would be reasonable. The concerns that are shared by the members of the community and the FDA would be if people were asked to donate blood for other people, with a similar sense of urgency, because of the concern over the accurate receipt of the blood donors' screening, that people are not donating for reasons other than altruism, because of the studies that have shown that when people are asked to donate and are urged to donate perhaps a little too much, that they may not be 100 percent truthful in the donor history.

It is a very complicated issue. But for autologous, as you appropriately point out, it would be reasonable to encourage people to donate their own blood for surgery that is planned.

Mr. Porter. Thank you, Dr. Snyder. I have taken much more time than I should, but I am interested, obviously, in the subject.

Dr. Snyder. Thank you very much.

Wednesday, January 28, 1998.

WITNESS

ALAN G. KRAUT, Ph.D., AMERICAN PSYCHOLOGICAL SOCIETY

Mr. Porter. Allen G. Kraut Ph.D., Executive Director of the American Psychological Society.

Mr. Kraut. Mr. Chairman, I am delighted to be here on behalf of the members of the American Psychological Society, many of whom receive NIH grants for such topics as brain behavior, addiction research, human development, aging, mental illness, hearing and vision research and chronic pain, to name just a few.

I ask that my written statement be entered into the record and I will just summarize here.

Let me begin by expressing our sincere thanks for the increase you have already given NIH, and to say that we will work hard with you, including visiting the Committee on the Budget, to double the NIH budget over the next 5 years.

As part of the Ad Hoc Group for Medical Research Funding, we are asking for a 15 percent increase in NIH as a first step towards that goal. But can NIH absorb this increase so quickly? I know that behavioral research stands ready. We are poised, both in terms of the role behavior plays in serious health problems and in the field's capacity to proceed in many important directions.

Last fall, Mr. Chairman, during your hearings on the mind, body, and health, we were all encouraged to hear you talk about finding ways to open the door to increase NIH's receptiveness to behavioral science research. Let me suggest that one way would be to make this open door theme a standard part of your conversations with Institute directors as they appear here in front of you. We think that even a single consistent question from you, such as can you tell me how you might be encouraging behavioral research in your Institute, would send this important message.

Increasing NIH's receptiveness is my main concern today. Some of our Nation's most critical health questions involve behavior: What goes on in the thinking of young people that leads them to start drinking, smoking, taking drugs? When do we acquire patterns of behavior that may be with us for the rest of our lives? What about connections between stress and health? How does genetics interact with behavior? What can we do to help memory as we age?

There are many others, but NIH resistance to the science that addresses these kinds of questions continues, despite recommendations from you, the National Academy of Sciences, even from its own Institutes. One example is how NIH responded, or rather didn't respond to recommendations from the National Academy of Sciences to increase training for behavioral scientists specifically through national research service awards.

In a congressionally mandated assessment of training needs, the National Academy said that the size of NIH stipends should be increased and that the number of awards for behavioral science and for several other areas also should be increased. Since 1995, this committee and the Senate committee have been asking NIH to implement those recommendations, and after a 3-year delay in responding, the NIH now says the amount of money awarded in the NIH stipend will be increased but not the number of awards in behavioral science or in other areas. NIH cites budget concerns for this selective implementation, saying that neither National Academy members nor Congress ``fully appreciated the costs.''

What are the costs? The National Academy's behavioral science recommendation to add fewer than 400 trainees would add about $4 million to the NIH budget, spread over 3 years and across all the Institutes. The cost clearly is not the concern here. So once again we ask the committee to encourage NIH to increase the number of their research service awards.

I should note that several Institutes have their own recognized needs for more behavioral researchers. With

encouragement from this committee and from the Senate they have developed small grants called BStart that are awarded to new Ph.Ds in behavioral science. We ask you to continue to encourage the use of BStart throughout NIH.

NIH now has an Office of Behavioral and Social Sciences Research. That is the logical place to take a lead on these training objectives and on cross-cutting behavioral research priorities. But OBSSR's budget is tiny, only $2.6 million. We ask that that budget be increased, even to approach $20 million. We are in an era of exceptional promise in behavioral science, but we need a more encouraging Federal environment in order to realize its potential.

In my written statement, I have asked for your support for the behavioral science initiatives that are taking place in several individual Institutes. But despite this activity, NIH still needs to recognize that behavioral science is a core element in its mission of research and public health.

This committee has shown extraordinary largesse in the annual NIH budget and we are very grateful for that support. Now we are asking you to encourage NIH leadership to take meaningful steps to ensure that the health of the Nation receives the full benefit. Thank you.

[The prepared statment of Alan Kraut follows:]

[Pages 159 - 170--The official Committee record contains additional material here.]

Mr. Porter. Mr. Kraut, thank you for your excellent statement. I have to say that obviously I agree with where you want to go. The process by which the Congress interacts with NIH and attempts to put its opinion into their thinking is a very complex and subtle. We do not feel that it is up to us to tell NIH what to do. They are scientists and we are not.

We do have matters that we are very concerned with personally, and that we encourage them to address. The hearings or briefings that we had on the mind and its role in health and healing was meant to convey a message to them that this is an area that we think has been neglected in a broad sense, and to encourage them to be more responsive. So we will continue to press on that process without the heavy hand of direction. We will have to see what comes of that, but it is something that is part of a much broader process.

We realize also that NIH doesn't exist in a political vacuum within the scientific community either, and that scientists are at all times attempting to influence the directions of NIH and the priorities that NIH undertakes. So it becomes an even broader process where we all kind of impact this great institution that we all admire and respect and try to move it a little bit in the direction that we think it ought to go. We appreciate very much your testimony, again, and thank you for being with us. We will do our best to be responsive.

Wednesday, January 28, 1998.

WITNESS

KAREN MURRAY, COALITION FOR HERITABLE DISORDERS OF CONNECTIVE TISSUE

Mr. Porter. Karen Murray, member, National Marfan Foundation and Chair, National Marfan Foundation's Have-A-Heart Campaign, testifying in behalf of the Coalition for Heritable Disorders of Connective Tissue.

Mrs. Murray. Good morning, Mr. Porter. I am Karen Murray, a member of the National Marfan Foundation, member organization of the Coalition, which represents more than one-half million Americans affected by heritable disorders of the connective tissue. Marfan's syndrome is one of 200 such disorders which include names most of us have never heard of unless or until a family member is diagnosed with one.

My son Michael was born August 13, 1991, 6 years ago, in one of the top hospitals in New York City. He was born with a dislocated hip, long fingers bent backwards at the knuckle, and an indented chest bone. I overheard the physicians discussing among themselves, but not directly with me, the possibility of Marfan syndrome. They sent Michael and me for echocardiograms, which are scans of the heart, pronounced us fine, and released us from the hospital.

The same doctors continued to follow Michael for the next 5 years, during which time he grew faster, longer, taller, and more awkwardly than all of his peers, and his indented chest became more pronounced. I went to all kinds of specialists, all but a cardiologist. I would constantly describe Michael's symptoms: Why is he so tall, thin, awkward, loose ligamented, with an indented chest, long fingers, arms, and legs? I was told to let it go, he is a beautiful, healthy child. But I knew there was something wrong.

For Michael's fifth birthday, I bought him an Apple computer which came with a free CD ROM called the Family Doctor. Late one night, when he was sleeping, I clicked into it. As I read the first paragraph under Marfan syndrome, I recognized the word Marfan syndrome; children with Marfan syndrome grow taller than their peers. They have indented or protruded chest bones. Fingers are disproportionately long, excessive joint mobility, muscle weakness, and so on.

The very next morning, after not sleeping, I brought him back to the same prominent New York City hospital where he was born and 5 hours later, after demanding an echocardiogram, my diagnosis was confirmed. Michael's aorta was indeed dilated and he did indeed have Marfan's syndrome.

Marfan's syndrome is a genetic disorder that affects the connective tissue throughout the body. In almost all cases it affects the heart and the aorta. Over 500,000 Americans are affected by Marfan's syndrome and related connective tissue disorders. At the time of Michael's diagnosis his aorta was already dilated. Severe dilation can lead to dissection, which is what we know as an aneurysm.

If medical personnel can't recognize the signs, the outcome is usually fatal. My point is this. Doctors at the best hospital in New York City, extremely aware of Marfan's syndrome and who suspected Marfan's syndrome at birth, failed to make the diagnosis. In the hands of the best medical personnel in

New York City, my son Michael slipped away. Had I not heard the word Marfan or bought him a computer, Michael would have been another statistic in his teens.

But it doesn't have to be that way. Although Marfan's syndrome is incurable and a progressive disorder--which is difficult for me to say those words--it is diagnoseable and treatable. So I have hope. As a parent of a 6-year-old Marfan child, I am nervous but optimistic that Michael will be okay. I now know to have his heart monitored every 3 months. I have him on medication in the hope that his aorta will be less stressed.

I live daily with the fear of when or how often will Michael's aorta dissect. Marfan's syndrome also affects all tissue throughout the body and presents orthopedic problems such as loose joints, scoliosis, elongated, uneven bones in the ribs, chest wall, spine, hips and legs. I cannot express as a mother the concern and the amount of questions I have.

There is still so much I don't know, and I am often told, I am sorry, we haven't researched that yet, especially not in children. Most children who go undiagnosed and untreated die at a young age. Today, tens of thousands of children go undiagnosed. Before Michael was born I never heard the word Marfan. I never thought about connective tissue.

Now there is not a night that I don't fall asleep without wondering or worrying about the fact that I am giving my son calcium channel blockers every single day in the hope it is helping his aorta, but what are the side effects after years of calcium channel blockers? No one can tell me. I keep asking if calcium channel blockers are okay for children. They don't know. There is no research.

Can and should Michael exercise at all? Can he take a regular gym class? They don't know what to tell me. What is more effective, surgery or a brace for his scoliosis? Do children with Marfan syndrome have weak tissues in their respiratory system? Is that why my son also has asthma, since it is not in my family? Why do Marfans' lungs collapse? Since Michael has so many orthopedic issues, what can I do to help him live a life of less chronic pain? I am scared to have another baby, but I would love to. Are there tests I can take to determine the health of the fetus?

Research is needed in all of these areas. It is essential. Undiagnosed Marfan patients end up in the emergency room. The emergency room staff does not know what to look for and most Marfan patients die. I am fortunate that I at least know that he is diagnosed. The key is to build awareness and educate the medical community, fromOB-GYNs to pediatricians to emergency room doctors, so they can recognize and diagnose Marfan's syndrome. Early diagnosis and careful daily management is critical in order to preserve and enhance the life of a Marfan patient.

Similar challenges are faced by other heritable disorders of connective issues. The advances in genetic research today bring hope to the one-half million individuals affected with these disorders. Yet more dollars are needed. The Coalition supports the proposal of the Ad Hoc Group for Medical Research Funding, which calls for a 15 percent increase in funding for the NIH in 1999 with a view towards doubling the budget over the next 5 years. Please help fund these important programs so we can learn more about how to care for Michael and so the

medical community is more aware of Marfan syndrome and heritable disorders of connective tissues, so that lives can be saved. Thank you.

[The prepared statement of Karen Murray follows:]

[Pages 174 - 181--The official Committee record contains additional material here.]

Mr. Porter. Mrs. Murray, I can't think of a more compelling case for providing resources for both research and helping the medical community understand and diagnose this disease. We very much appreciate your testimony.

I think Marfan's only came to the attention of the American people recently, in respect to Abraham Lincoln. There was some thought that perhaps he was a victim of that disease. I think they even were going to--and I can't remember the outcome--look at the bone, the DNA.

Ms. Murray. They still are. It is suspected that he had Marfan's syndrome, along with Chris Patton and lots of other famous people. They suspect John Larsen, the director and writer of Rent, and lots of other famous people.

Mr. Porter. The fact that famous people may have such a disease very frankly often helps the American public to understand the disease better. It gets their attention. I often tell--we have a lot of celebrities come and testify before this subcommittee regarding various diseases, and I think that helps a great deal for people to understand the disease, and gets them focused on the fact that even famous people suffer from these diseases, and that I think helps build us a support base for the research that we need to address them.

Ms. Murray. And more awareness.

Mr. Porter. Thank you for coming to testify. I really appreciate that.

Wednesday, January 28, 1998.

WITNESS

DEBORAH KLEIN WALKER, ASSOCIATION OF MATERNAL AND CHILD HEALTH PROGRAMS

Mr. Porter. Deborah Klein Walker, Ed.D, President, the Association of Maternal and Child Health Programs, testifying on behalf of the association.

Dr. Walker. Thank you. I am Deborah Walker, President of the Association of Maternal and Child Health Programs. In Massachusetts, I serve as the Assistant Commissioner of Family and Community Health within the State Health Department. Thank you very much for the opportunity for us to appear before you today.

On behalf of the Association, I appreciate the subcommittee's support of the maternal and child health services block grant. The block grant forms the essential framework on which States have built and maintain their systems of care for women, children and youth.

For over 60 years the MCH programs have helped to reduce maternal and infant mortality, improve the health of newborns by preventing life-threatening diseases, improve the health status of school-aged children, prevent adolescent pregnancy and other at-risk adolescent behaviors, and assist children with special health care needs.

State MCH programs carry out core public health prevention activities, as well as provide direct services for women and children who lack the necessary health care. Investments in public health, including MCH services, is cost-effective and results in improved health outcomes.

For example, newborn screening prevents chronic diseases and disabilities through early detection, diagnosis, and treatment of disorders. In Illinois, 99 percent of all newborns are screened for at least 6 disorders, including sickle cell anemia. Tobacco use, exposure to environmental tobacco smoke, poses exceptional and immediate risk to pregnant women and children. In 1995, the estimated costs of birth complications attributed to smoking were conservatively estimated at $1 billion. State MCH programs have worked in partnership with community-based groups and the private sector to prevent and end nicotine addiction.

I would like to also add, you have heard a lot about a very important research, but it takes an infrastructure to get the results of this research to the public at the lay level in the community. The MCH block grant is such a vehicle. MCH funds have supported major campaigns like the ``Back to Sleep Campaign,'' which has drastically brought down deaths due to SIDS, and is also funding campaigns on the importance of folic acid for pregnant women, so that spina bifida will be prevented.

In addition to these public health prevention strategies, the MCH block grant directly serves over 17 million women and children, including almost 1 million children with special health care needs. The health of our Nation's pregnant women and children has improved dramatically over the 50 years.

Through advancements in medical technology and improved access to care, we have seen significant reduction in many adverse health outcomes. However, many things still fall short of where we want to be, especially in our underserved and minority populations. For example, in the last 15 years, infant mortality for both whites and blacks has decreased considerably, but the gap between whites and blacks has actually increased. Smoking rates for adolescents are going up, injuries remain the leading cause of death for children and women, and infants are at an increased risk for things like HIV and AIDS.

Last year, and we want to compliment you, Congress took significant steps to address some of these problems through passage of the State children's health insurance program. This health coverage expansion presents States with tremendous opportunities. State MCH programs are very much partnering with State Medicaid agencies during this implementation stage to figure out best how to approach and spend those funds within each State. However, with this tremendous expansion we still know that not all children will be covered, and we also know that those who are even covered by insurance will not have all

the necessary services they need. Therefore, the MCH block grant is still needed in every State.

The congressional budget estimated that the new law wouldcover an estimated 3.4 million uninsured children when it is fully implemented. This leaves 3.6 million uninsured children still out there. The children's health insurance program again does not provide access to care, outreach and intake, services to uninsured pregnant women, underinsured children, especially those with special health care needs, comprehensive services for special health care needs, home visiting services, school health services, and adolescent health services, just to name a few.

These are responsibilities that the MCH block grant will continue to address, in addition to the fact that the MCH programs will continue to ensure the availability of public and private providers in rural and underserved areas, support and coordinate services for children with special health care needs, and get pregnant women and children into these health insurance programs, and get them signed up so they will receive the benefit of the program.

Mr. Chairman, our Nation is making strides in the health status of women, infants, children, youth and their families, but we still have a long way to go. Through wise investment in the maternal and child health services block grant we can see further improvements in the health of mother and children. This MCH block grant is a flexible block grant to States. States have used it successfully to develop local systems of care which have addressed these issues.

The MCH block grant is in fact the point of accountability for the entire MCH population in each State. For these and other reasons, the association recommends a funding level of $705 million, only a 3 percent increase over the last year. With sufficient funding, the maternal and child health services block grant will continue to play a vital role in improving the health status of all children and pregnant women in every community in every State of this Nation. Thank you.

[The prepared statement of Deborah Walker follows:]

[Pages 185 - 192--The official Committee record contains additional material here.]

Mr. Porter. Dr. Walker, that was a very articulate statement. We will, as you know--in a certain sense you are preaching to the choir, but we will do our very best to meet that goal.

Dr. Walker. Thank you very much.

Mr. Porter. Thank you for coming to testify.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Wednesday, January 28, 1998.

WITNESS

ROGER BURNS, PRIVATE CITIZEN, HIMSELF

Mr. Porter. Roger Burns, a private citizen testifying on his own behalf. It is unusual, and we welcome you.

Mr. Burns. Thank you, sir.

Mr. Chairman, my name is Roger Burns. I publish a widely read newsletter with a readership of over 10,000 on the topic of chronic fatigue syndrome. I am also a leader in the effort to change the name of this illness. I will today make some recommendations to you about the name change issue which has been a policy interest of your committee.

As you are aware, there is a strong stigma associated with the name chronic fatigue syndrome. Outdated science reports have in the past prompted misinformed notions of ``it is all in their minds,'' et cetera, on the part of the public, employers, disability insurers, and by all too many medical professionals, despite recent scientific research that underscores the seriousness of this disease.

This stigma adds a great deal to the disruption of the patient's lives, often obstructing the delivery of needed medical care, interfering with the ability to collect merit insurance claims and obstructing family life. Sadly, the scientific knowledge that has been accumulated, which does validate this emerging illness, has been disseminating very slowly to the general medical community and to the public.

I issued a survey last year to CFS patients about the change-the-name issue, which was graciously co-published by the CFIDS Association of America. The results from 668 respondents showed that over 90 percent of those respondingwant the current name to be replaced, and that many specific alternatives were deemed suitable to overcome the stigma of the current name.

Many CFS patients are grateful that your committee's report for fiscal year 1997 asked the HHS Secretary to, and I quote, ``convene a committee for the purpose of examining the name change issue, and to report back within 6 months of the bill's enactment with recommendations for a new scientific name or eponym that more appropriately describes the illness known as chronic fatigue syndrome.''

Those scientists who are the most familiar with CFS do say openly at their medical conferences that they now know that this is a serious illness. But this current state of knowledge is not yet widely understood by most doctors. What better vehicle could there be to help eradicate the stigma of CFS than for the Department of HHS to hold a press conference to declare that, ``We now know, given a decade of accumulated evidence, that CFS can be a very serious illness, and to underscore our new knowledge, we are changing the name of this illness''?

To fulfill the request of this Appropriations Committee, the HHS Secretary delegated the name-change issue to her CFS coordinating committee, which, however, voted at its October 2, 1997 meeting to postpone indefinitely any change of name until such time as more scientific evidence might appear to justify the choosing of a wholly new physiologic-based name. That committee then disbanded its working group on this topic.

The CFS coordinating committee's public discussion gave little attention to the already-established alternative names

already used in scientific literature for referring to this illness, nor to the possibility that an eponym might be chosen. In short, the most difficult option was focused on. The committee did not discuss--the coordinating committee did not discuss the stigma of the current name and its burden on the patients, which was the original reason for calling for a change in name. In addition, public testimony was excluded until the end of the meeting, when the decision to suspend the name-change issue had already been made.

I believe there are two reasons why the CFS coordinating committee suspended the name-change issue. One, there was no permanent Assistant Secretary for Health during 1997, when the coordinating committee took up this issue. The Assistant Secretary for Health chairs the CFS coordinating committee. Therefore, there was not sufficient leadership within that committee to ensure that the name change was given a complete hearing.

Two, none of the scientists who serve on the CFS coordinating committee can afford, as individuals, to recommend a specific alternative name. These scientists are already putting their careers at great risk by focusing their research on CFS. They could be throwing away their careers by becoming any more prominent in this field than they already are. That is right, scientists who study CFS are stigmatized by other scientists.

With these facts in mind, I recommend the following steps to the Appropriations Committee: A, when the new Assistant Secretary for Health is in place, it will be very important to sensitize that official to the needs of the CFS community and about the name change/stigma issue in particular.

The only way to make deliberate progress in legitimizing this disease is to have leadership from some official who has the respect of the research community, but who is also independent enough that their personal career does not depend on getting published as a researcher. The ideal official for this task would be the Assistant Secretary for Health. Please help to motivate and sensitize the new Assistant Secretary when you discuss HHS matter with him in his appearance before this committee later this year. For our part, those of us in the CFS community will work to educate the new Assistant Secretary about these issues in detail.

I have one further point to make. The CFS coordinating committee is truly incapable of recommending any alternative name in the foreseeable future because that committee is comprised largely of government bureaucrats and vulnerable researchers, none of whom can afford to recommend anything that might be perceived as too innovative in this politicized field, even merely changing the name of the illness.

Yet some participation by scientists will be essential in giving credibility to the recommendations of a name-change panel. Therefore, it would be most helpful if the Appropriations Committee were to renew its call for a new name or eponym, and to ask the HHS Secretary to appoint a ``committee or workshop or a forum'' that would include not only scientists but also general practitioners of medicine, and patients who are advocating a change of name for the illness.

I thank you for your attention.

[The prepared statement of Mr. Roger Burns follows:]

[Pages 196 - 198--The official Committee record contains additional material here.]

Mr. Porter. Mr. Burns, I am not sure you are aware of this, but this whole issue was one that I began working on when I first began as a member of this subcommittee because a constituent of mine came to me and said his daughter had this health problem that the medical community was not recognizing for what it was, and we began then pressing on NIH, through language in our bill and later on with direction, to conduct research.

At the time it was called Epstein-Barr syndrome. No one wanted to take it seriously, and by pressing on the process a great deal, they began to do some work and found out that it was in fact a serious disease. So I am very interested in what you are telling me. We will continue to press on this process to try to get a decision.

Now, tell me why chronic fatigue syndrome is not a description that you want to stick with.

Mr. Burns. A couple of reasons. One is that there was a lot of brouhaha in years past about CFS not being real, about it just being depression, et cetera. That has glommed onto the current name.

It can glom on easily to the current name, because although fatigue has a broad connotation in the field of science, in everyday language, fatigue just means mildly tired. So the technical scientists would say that, well, it is an appropriate name if you look it up in a medical dictionary, but it is so easy to----

Mr. Porter. Not taken seriously, as it should be?

Mr. Burns. Yes.

Mr. Porter. One of the reporters that had covered Congress from my district, but here in Washington for years suffered from this disease, was given six months medical leave to try to cope with it, and ended up finally retiring, because he couldn't cope with it. So it is, in my mind, a very serious disease that afflicts many, many Americans. Many are unaware that that is what is afflicting them.

As I say, we take it seriously here and we will do everything we can to move this process along and work with you on it.

Mr. Burns. Yes. Thank you very much.

Mr. Porter. Thank you for your testimony.

Wednesday, January 28, 1998.

WITNESS

GERALD J. CHADER, Ph.D., M.D.h.c., NATIONAL ALLIANCE FOR EYE AND VISION RESEARCH

Mr. Porter. Gerald J. Chader, Ph.D., M.D., Chief Scientific Officer, Foundation Fighting Blindness, representing the

National Alliance for Eye and Vision Research.

Good afternoon.

Dr. Chader. Mr. Chairman, for the last year I have been the chief scientific officer of the Foundation Fighting Blindness. It is based in Baltimore. It is a nonprofit foundation funding basic research and clinical research to blinding diseases. Before that I did about 25 years of research in ophthalmology at Harvard and at the National Eye Institute in Bethesda.

Today, I actually represent the Association for Research in Vision and Ophthalmology, which is an association of 10,000 members of all the leading scientists and clinicians doing ophthalmic work. In turn, ARVO and my foundation are part of the National Alliance of Eye and Vision Research, which is an umbrella organization representing 28 professional lay advocacy and industry organizations dedicated to curing blindness. So we are all in this together.

Thanks to your support over the last 25 years, a solid basis of work funded by the National Eye Institute has put us on the verge of truly spectacular increases and advances in treatments and cures of several major eye diseases.

In the very short amount of time I have, I simply want to tell you three things. First of all, the magnitude of the problem of blindness; secondly, that indeed, we do have a superb, long-range plan. It pinpoints the very best opportunities in curing blinding diseases, as well as addressing the economic and societal impact of blindness and impaired vision. Third, I want to give you just one example of an area where new funding can have a huge impact in the next year or two.

First of all, what about the magnitude of the problem? In the United States today, with over 1 million legally blind Americans, 80 million Americans have potentially blinding eye diseases, 120 million Americans wear glasses or contact lenses, and a full 12 million suffer from visual impairment that can't be corrected by glasses.

Let me say that I am not wearing glasses, so this is not a normal situation with aging, and I do see that you use yours very sparingly. So this is a disease process that has a major impact.

Mr. Porter. No, sir, I am wearing contact lenses, with one reading lens. This is additional.

Dr. Chader. I may be the exception to the rule, but I don't wear glasses, but it is a pathological process. It is not normal with aging.

The economic and societal impact of these figures is staggering. The annual cost of these disorders is in excess of $38 million. Of course, the societal impact, for example, the basic quality of life, that is incalculable, particularly in our fragile aging population, where good vision is a necessity for independent living, and certainly for self-dignity.

The second question, do we have a plan, certainly. On this issue, I would like you to very closely examine the Eye Institute's national plan for the years 1999 through 2003. This is the 7th such plan that the Eye Institute has put together where all the stakeholders in the eye community have input. I have looked at it twice already and given my best shot as such. Basic scientists, clinicians, and all researchers have a word

in this. The answer to this question then is a resounding yes. We certainly do have a plan. It is cogent, practical, practicable, and definitely will deliver a huge payoff in the next few years if properly funded.

Finally, I would like to give you one example of a major blinding condition where we do and perhaps can have a morning impact. That is with macular degeneration. MD, macular degeneration, is a disease that destroys a person's central vision by killing off what is called the macular region of the neural retina.

If you put a fist up close to your eye and then try to look out the periphery, that is what patients see or don't see with macular degeneration. Then slowly the rest of the eye goes as well. The total number of Americans with macular degeneration runs into the millions, and fully one-third of all Americans over the age of 75 show some signs of macular degeneration.

This is a problem now of epidemic proportion as our population ages and as our baby-boomers mature. Statistics show that macular degeneration does increase 100-fold from the age of the early sixties through 80 to 84. The latter, I am sure we all wish to get into that group sooner or later, and don't wish to be blind.

Working myself in this area of research for 24 years, I know for a fact that new scientific information gained just this last year brings us very close to treatments and cures. We now know that macular degeneration is found in family clusters, therefore probably making this a genetic disease. Six months ago we hardly even thought about that. Then we have a new major gene that has recently been found, and we have certain other areas of gene therapy, medical, pharmaceutical, and alternative therapies, where we can apply them.

In conclusion, the magnitude of this problem, and of cataracts, which I have not even talked about, and of the 3 million people with glaucoma, predicates that there are really wonderful advances that we are on the verge of. We have genes for many of these diseases now, for gene therapy and other types of therapies. We do hope, and we very much support, a 15 percent increase in the overall NIH budget, and certainly the National Eye Institute's budget.

I would like to stop here then and ask if you have any questions. Thank you.

[The prepared statement of Gerald Chader follows:]

[Pages 202 - 213--The official Committee record contains additional material here.]

Mr. Porter. Dr. Chader, as I said earlier, we don't consider these things in a vacuum. You pointed out that I have had poor vision for a long time. My wife's mother has retinitis pigmentosa, so we have another vision problem, though it is not as prevalent as the ones you have mentioned, and it is something--she is in effect legally blind. So I understand, I think, the importance of these research dollars, and have understood from the testimony of the National Eye Institute that real progress is being made, and more progress is possible

if we can get the research dollars to support it.

Dr. Chader. Absolutely. My foundation is called the Foundation Fighting Blindness, but 2 to 3 years ago it changed its name from the National Retinitis Pigmentosa Foundation to embrace and encompass all of the retinal degenerations, the millions now, with macular as well as the hundreds of thousands with retinitis pigmentosa.

As its chief scientific officer, I have a canned talk as such, which I won't deliver, I will spare you that, but basically there are three major areas of research, where not only can we possibly stop and halt retinitis pigmentosa and all the macular degenerations, but actually reverse the process, perhaps for your mother-in-law, through implants, through retinal transplantation of photo receptor cells and all.

So we hope to not only stop the progress of these diseases, young, middle-age, but also reverse the disease process as well. If you have further questions in the future, I will be very happy to talk with you about that.

Mr. Porter. Thank you so much, Dr. Chader. We appreciate your testimony this afternoon.

Wednesday, January 28, 1998.

WITNESS

DONALD M. PORETZ, M.D., INFECTIOUS DISEASES SOCIETY OF AMERICA

Mr. Porter. Donald M. Poretz, Chair of the Public Policy Committee of the Infectious Dieseases Society of America, testifying on behalf of the society.

Dr. Poretz.

Dr. Poretz. Mr. Chairman and members of the subcommittee, I am Dr. Donald Poretz. I currently serve as chair of the Public Policy Committee of the Infectious Disease Society of America. Infectious disease physicians do care for patients with serious infections such as AIDS, meningitis, heart valve infections, bone and joint infections, and so on.

Thank you for allowing us to testify today regarding fiscal year 1999 funding for the National Institute of Allergy and Infectious Diseases and the Centers for Disease Control and Prevention.

Infectious diseases are the leading cause of death worldwide and the third leading cause of death in the United States. An investment of such sufficient dollars in these valuable programs now will pay significant dividends in the future to the American people by dramatically reducing health care costs and improving the quality of life for millions.

We urge the subcommittee to continue to demonstrate leadership and foresight in this area by appropriating much-needed funding increases in these programs for the coming fiscal year, in recognition of the lives and dollars that ultimately will be saved.

Overall, the Society wishes to stress the importance of basic and clinical research conducted by NIH and NIAID in the area of infectious diseases, as well as the enormouscontribution to prevention of infectious diseases by the CDC.

It is, of course, impossible to cite every contribution of

these two stellar agencies in the diagnosis, treatment, prevention, and control of infectious diseases, but let me give a few examples.

Emerging infectious diseases, as the media attests, new and dangerous infectious diseases continue to challenge us. These examples include hantavirus, Ebola virus, Lyme disease, reemergent tuberculosis, other drug-resistent infections, particularly in hospital, and the recent outbreak of H5N1 avian influenza virus in Hong Kong.

The Society supports continued incremental increases in funding for the CDC action plan that emphasizes improved disease detection and response for emerging infectious diseases, and supports the new infectious diseases laboratory building at the CDC.

AIDS research. As you know, the NIAID is making great headway in AIDS research by supporting research in the use of combination drug therapies that appear to control the disease better. In the United States, AIDS deaths dropped 23 percent, from 1995 to 1996 and new AIDS drugs declined by 6 percent, due in part to the use of potent antiretroviral drugs.

As an aside, I am in private practice in northern Virginia. My practice has seen over 1600 HIV patients in the last 12 years. We used to run 10 or 12 patients in the hospital at any given time. We now may have one patient in the hospital because of these new therapies. They have indeed been dramatic.

Increased funding is necessary to continue this progress. Vaccine research and development. Immunization is one of the most cost-effective interventions in the health care field. For every $1 spent on immunization, as much as $29 can be saved in direct and indirect costs. Recent scientific advances have enabled the development of new vaccines and significant improvements in the efficacy and safety of existing vaccines.

Increased funding will enable NIAID and the CDC to develop and deliver new and safer vaccines for many other serious infections, including AIDS, sexually transmitted diseases, streptococcal disease, tubercular infections, and so on. In particular, we urge consideration for special short-term grants for possible development of an AIDS vaccine.

In addition, one of the most desperately needed vaccines is for malaria, especially since drug resistent strains of the parasite are spreading. Again, even in my practice we see several cases of malaria a year. In the Washington area people travel all over the world and bring back all sorts of disease.

STD research, prevention and treatment. A recent Institute of Medicine report notes that of the top 10 most frequently reported diseases of the United States, of these, 5 are sexually transmitted. Approximately 12 million new cases of STDs occur annually. The U.S. has the highest reported rate of curable STDs in the developed world.

The cost of ignoring STD treatment is enormous, estimated by the Institute of Medicine report to be about $10 billion a year. Moreover, curable STDs when left untreated continue to increase spread of HIV, and lead to sterility and infertility. Again, in my practice, you would be amazed at the number of young people, high school age and college age, who come for various sorts of infectious, various types of sexually transmitted diseases.

Training and career grants, the biomedical discoveries being made today had their origins in the basic biomedical research training conducted in the past. Continued progress and leadership in combatting infectious diseases are directly related to the ability to train and retain new investigators in the field.

This subcommittee is well aware of the fiscal challenges confronted by academic health centers. More than ever before, rigorous support of training grants and research and career development awards are essential to ensure the continuation of basic biomedical research necessary to yield a bounty of knowledge to be capitalized on tomorrow.

The Infectious Disease Society of America very much appreciates the opportunity to testify regarding the importance of adequate appropriations for research, prevention, and treatment of AIDS and other infectious diseases. I would be glad to answer any questions if you have any.

[The prepared statement of Dr. Donald Poretz follows:]

[Pages 217 - 223--The official Committee record contains additional material here.]

Mr. Porter. Dr. Poretz, we appreciate your statement. When we first were required to make very significant cuts in the overall spending of the subcommittee in 1995 in order to help balance the budget, there were only 10 line items out of about 800 where we were able to give increases. One, of course, was NIH. The other was CDC. So I think the subcommittee puts the entire subject of infectious diseases through public programs and through research at a very high priority, and we will do our very best to continue that commitment.

We understand how important it is, and your testimony reminds us that it is very, very important work that affects so many lives, not only in our own country but around the world, that we have to provide that kind of support. We will do our best to do that.

Dr. Poretz. Thank you very much.

Mr. Porter. Thank you very much for testifying.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Wednesday, January 28, 1998.

WITNESS

ORA PESCOVITZ, M.D., PUBLIC POLICY COUNCIL

Mr. Porter. Laura Pescovitz, M.D., professor of pediatrics, physiology, physiology/biophysics, director of pediatric endocrinology and diabetology. Did I get through that? Indiana University, testifying on behalf of the Public Policy Council.

Dr. Pescovitz. You did it.

Mr. Porter. Welcome, Dr. Pescovitz.

Dr. Pescovitz. Thank you very much, Mr. Porter. I really appreciate the opportunity to present testimony today on behalf of the pediatric research community.

As you have already acknowledged, my name is Ora Pescovitz. In addition to being all those things that you have mentioned, I am also a member of the Scientific Advisory Committee of the Ad Hoc Group for Medical Research Funding.

I am here today representing the public affairs coordinating body for the three major pediatric academic societies and research societies. Our organizations represent thousands of pediatric investigators whose collective goal is to improve the quality of life for all of America's children.

On behalf of these organizations, and as an investigator myself, I am here today to speak about the importance of research funding for pediatrics, and also for the training of pediatric investigators.

Why should we fund pediatric research? Although infants and children are leading healthier lives today, there are still many pediatric diseases that do not have a cure or for which treatment is inadequate. Modern therapy for relatively common diseases like cystic fibrosis or juvenile onset diabetes is cumbersome, costly, and stressful for children and their families.

Although it is obvious that we want to improve the health of children for their own sake, it may be less obvious that improvements in pediatric medicine will have far-reaching implications on the societal and economic costs of adult diseases. Let me just mention one example of how a strengthened investment in pediatrics can benefit adults as well as children.

Osteoporosis is a crippling bone disease that occurs most commonly in post-menopausal women. The morbidity and costs from osteoporosis are not incurred during childhood. Nonetheless, this disorder can really be considered a pediatric condition. This is because all of us deposit bone minerals throughout childhood, adolescence, and early adulthood. In fact, by the age of 30, we have each achieved our peak bone mass. After that, bone mass declines throughout the rest of adult life.

Therefore, deficiencies in bone mass in childhood will predispose individuals to osteoporosis in adulthood. If we could improve acquisition of bone mineral during childhood, we might actually be able to prevent many forms of adult osteoporosis.

Why should we fund pediatric investigators? As mentioned earlier today by Dr. Kelly, there is a growing concern among our academic colleagues that there is a looming crisis for the future of research in academic institutions and pediatric research in particular. Most pediatric research is performed at the Nation's medical schools, children's hospitals, and in the intramural programs of the NIH.

As the focus of academic health centers shifts away from the traditional roles of research, teaching, and patient care to one which is predominantly patient care, we are concerned that the quality of training of future generations of pediatric medical scientists may be impaired, and this in turn could jeopardize the future health of our entire population.

Now, what can we do to promote pediatric research, and also

to preserve the training of pediatric investigators? The entire pediatric community applauds the ongoing commitment of Congress, through the leadership of this committee in particular, to increase NIH funding. We support all of the recommendations of the Ad Hoc Group for Medical Research Funding, but in particular, we would like to recognize your committee's pivotal role in making pediatric research a priority at the highest levels of the NIH by establishing a pediatric research initiative that is currently funded at $38.5 million. We encourage you to maintain this commitment and to increase the funding for the pediatric research initiative to $50 million in 1999.

My written testimony reflects just a few examples of the many ways that we believe these dollars should and can be used. Furthermore, we urge you to increase funding fortraining programs that will attract minority group students into the medical professions and encourage medical students to pursue careers in clinical and basic investigation. We want these programs to support young investigators and also we believe that they will enhance the quality of our mentors.

In conclusion, as a pediatrician and as a researcher, I know firsthand that there are many important pediatric research opportunities that promise significant return on investment, not only improved health for children today, but also economic productivity tomorrow as our children grow into adulthood.

Thank you for the opportunity to discuss the importance of pediatric research, and I would be delighted to answer any questions.

[The prepared statement of Ora Hirsch Pescovitz follows:]

[Pages 227 - 234--The official Committee record contains additional material here.]

Mr. Porter. Dr. Pescovitz, we very much appreciate your testimony in this morning's panel as well. I have to say that you and a number of other witnesses this morning have all mentioned the need to attract, to train, to encourage young investigators in respect to biomedical research, and we want to work very closely with you to try to continue to provide the resources that in fact do attract young people to scientific careers. That, I think, is a very, very high priority for the entire enterprise, so we appreciate your testimony this morning. Pediatric research is obviously of great significance, and we will continue to try to provide the kind of resources that can make a difference.

Dr. Pescovitz. We greatly appreciate that.

Mr. Porter. Thank you all for testifying. You all stayed within your time limits very, very well. We appreciate that. We stand in recess until 2 p.m.

Afternoon Session

Wednesday, January 28, 1998.

WITNESSES

DR. LORNE M. MENDELL, SOCIETY FOR NEUROSCIENCE
FRANKIE TRULL

Mr. Porter. The subcommittee will come to order. This is our second session of public witnesses, and as we begin the hearing, I want to remind witnesses of two provisions in the Rules of the House. In addition to their written statement, nongovernmental witnesses must submit a curriculum vitae and a statement of Federal grant or contract funds that they or the entity they represent have received.

If you have any questions concerning the applicability of this provision or questions as to how to comply, please contact our subcommittee staff.

In order to accommodate as many members of the public as possible, we have scheduled over 20 witnesses for each session and are still not able to hear from all who wanted to testify. Overall, we will hear from over 200 witnesses in this segment alone. As a result, I have to enforce the rule limiting testimony to 5 minutes very strictly.

Our subcommittee staff has a new device to time witnesses. We will time them, and we will do everything possible to stay within the time limit, and I would therefore ask that you keep this limitation in mind in consideration of the other witnesses that must follow you.

With that, we begin with Dr. Lorne M. Mendell, President of the Society for Neuroscience and professor of the Department of Neurobiology and Behavioral Sciences at the State University of New York at Stony Brook, testifying on behalf of the Society for Neuroscience.

Dr. Mendell.

Dr. Mendell. Thank you, Mr. Chairman. My name is Dr. Lorne Mendell and this is my colleague, Frankie Trull. I am the President of the Society for Neuroscience and professor at the Department of Neurobiology and Behavioral Sciences at the State University of New York at Stony Brook. I am testifying on behalf of the Society for Neuroscience, the largest scientific organization in the world dedicated to the study of the brain and spinal cord, consisting of more than 28,000 basic and clinical neuroscience researchers.

Mr. Chairman, we are very grateful for this opportunity to give our testimony, and I want to express our gratitude to this subcommittee and especially to you, Mr. Chairman, for the high priority that you have placed on continued funding for biomedical research at NIH. We were especially pleased, Mr. Chairman, by your comments late last year about providing a significant increase for NIH for fiscal year 1999.

We fully support the goal of doubling the budget of NIH over the next 5 years, as has been advocated by many in the Congress.

The field of neuroscience, only a quarter of a century old, has become well known to the general public through its major contributions to the welfare of our Nation of citizens. New insights and effective treatments have been developed forpreviously hopeless diseases. For example, current basic research has allowed us to understand mechanisms of pain so that various

remedies are being developed for people who suffer from chronic pain due to disorders of skin, nerve and joints.

Without adequate funding, our fight against neurological diseases and disorders such as Alzheimer's, Parkinson's, mental retardation, stroke, severe depression, schizophrenia and spinal cord injury, to name just a few, would suffer a serious setback.

As researchers, patient advocacy groups and Members of Congress work together, the Nation will become more familiar with the progress that is occurring in our laboratories and will recognize that funding is still needed to expand upon what we already know. If we can double the budget of NIH, we can change some of these sad, but all too familiar, stories into medical success stories.

Brain diseases affect more than 50 million Americans annually at costs exceeding $400 billion in direct costs for clinical care and in lost productivity. The more than 1,000 disorders of the brain and nervous system result in more hospitalizations than any other disease group. The prevalence of brain disorders in the United States, together with high annual costs for treatment, combine to make these conditions the number one public health problem now confronting the Nation.

Apart from improving the quality of our citizens' lives, the research conducted at NIH is highly cost effective. The estimated annual economic costs of neurological disease is staggering--for example, stroke at $40 billion, Alzheimer's at $90 billion and all mental disorders at $148 billion. My written testimony includes more examples.

NIH is working on an economic analysis to be available in the near future that highlights even more areas of cost savings.

We at the Society for Neuroscience realize the difficulty in finding money for biomedical research. However, results from basic neuroscience research are on the threshold of leading to important scientific breakthroughs in a number of brain diseases. To lose this momentum now would be detrimental to the health of the Nation. We feel that it is vital that the necessary funds are appropriated to continue to achieve the tremendous advances and breakthroughs that are within our reach. It is our hope that funding for all biomedical research will be increased as discoveries of one Institute carry over to work being done by other Institutes at NIH.

The main goal is to increase funding overall so that further progress can be made in the hopes of ending these debilitating disorders and diseases. It is for these reasons that I have mentioned, and many others that you will hear in the days to come, that we recommend a 15 percent increase over fiscal year 1998 for NIH and support the proposal for the Ad Hoc Group for Medical Research Funding.

Our recommendation is a first step towards doubling the NIH budget over the next 5 years. We recognize the difficulty in achieving this goal under current spending limits and encourage the Congress to explore all possible options to identify the additional resources needed to support this increase.

In conclusion, Mr. Chairman, the Society for Neuroscience is grateful for this opportunity to present testimony to this

distinguished subcommittee; and at this time, I will be pleased to answer any questions the Chairman or members may have.

Thank you again, Mr. Chairman, for your continued support.

[The prepared statement of Lorne M. Mendell follows:]

[Pages 238 - 245--The official Committee record contains additional material here.]

Mr. Porter. Dr. Mendell, thank you for your good statement. Because you are our first witness of the afternoon session, you get my sermonette. My sermonette goes this way.

If we have any hope of getting the kind of increase for funding for biomedical research or for other priorities within the jurisdiction of the subcommittee, we must have an allocation from the budget process that allows us those resources. The only way we achieve that is having impact on the budget process and achieving the levels indicated.

The President, in his State of the Union address last night, proposed to ramp up spending for basic research, not just biomedical research, but all basic research, and he was talking about a 50 percent increase over 5 years instead of 100 percent increase and his budget to provide spending--discretionary spending in any area has about $100 billion of new revenues involved, all of which, in my judgment, are highly problematical given the proclivity of the Congress not to want to raise taxes of any type, even tobacco taxes, which I favor.

So in the sense of this being a priority for the subcommittee, I think there is no question that it is, but the subcommittee needs help in the budget process in getting the resources we need to do what you are asking us to do. And so for everybody in this room who is interested in the programs before this subcommittee, not only biomedical research but all of them, that is where help is needed. That is where the message has to first be sent, and we can't do anything unless we have the resources to do it.

That is my sermonette. Thank you for listening. Thank you all for listening.

Dr. Mendell. All right. Thank you.

Wednesday, January 28, 1998.

WITNESS

RONALD NIESING, NATIONAL COUNCIL OF SOCIAL SECURITY MANAGEMENT ASSOCIATIONS, INC.

Mr. Porter. Our next witness is Ronald Niesing, President of the National Council of Social Security Management Associations, Inc. Mr. Niesing.

Mr. Niesing. Thank you, Chairman Porter, for the opportunity to present the views of the managers and supervisors who work in SSA's community-based field offices and teleservice centers across the country. Today, I will talk about the solvency issue facing Social Security, staffing in our offices, efforts to eliminate program fraud and abuse, and

the delivery of services to our constituents.

The mission of SSA is ``To promote the economic security of the Nation's people through compassionate and vigilant leadership in shaping and managing America's Social Security programs.'' The 3,200 managers and supervisors I represent want to share with you our vision, gained through experience working with the public every day, for managing the Social Security programs that now benefit millions of Americans.

The Nation is beginning a new debate about the future of Social Security. An agency goal is to ``strengthen the understanding of the Social Security programs.'' An informed public is crucial for this debate to reach a successful conclusion. All Americans should feel that they have a role in the financial planning for their futures.

Our members work with community leaders and organizations. We hear the questions and concerns expressed by your constituents. We are respected and involved members of our communities, and serve as a ready conduit for a public information campaign on solvency.

You, as a committee, need to ensure that sufficient tools and resources are in place for us to deliver the appropriate information.

SSA now faces a long-term crisis in management. Arbitrary goals have been established to reduce frontline managers and supervisors. This will crimp our ability to effectively discuss the future of Social Security in town halls, in classrooms, with local media, and with community civic groups.

Like politics, all education is local. More people will hear the message on Social Security reform from local sources rather than from the national media.

The Advisory Board has urged SSA to provide leadership on retirement planning, to work with employers and employees, and to strengthen the staff and promote the understanding of Social Security. These recommendations cannot be met while arbitrarily reducing managers and supervisors. In appropriating funding for SSA, we urge you to keep the upcoming solvency debate in mind.

SSA's strategic plan calls for the delivery of customer-responsive, world-class service. Our first aim is to deliver the best possible service to your constituents. Yet, less than half of the 65,000 employees who work for SSA are serving on the front lines in the 1,300 field offices and teleservice centers. We need to move more employees to direct service positions, to help process new claims, handle requests for Social Security numbers, combat fraud and abuse, and work with employers to ensure proper use of Social Security numbers.

Despite these needs, future agency staffing will cut 3,000 more field office employees, the people who serve your constituents. As appropriators, we urge you to keep those needs in mind as you deliberate the budget for SSA. I know that Social Security issues are the number one cause of constituent contacts. Will the public be getting the best value for its tax dollar by cutting 3,000 more employees from local offices while leaving current staff in place in large headquarters complexes and processing centers?

SSA has a goal of ``zero tolerance for fraud.'' This will be more difficult to achieve as we cut management and staff positions. At a minimum, we must keep all of the employees we

now have in place in the field. If SSA is to avoid situations like the Georgia family, where 181 members were receiving SSI benefits, we need to increase our community contacts and work with medical providers.

All of you have received letters and calls from constituents regarding lengthy delays in waiting for disability decisions. SSA is moving to modernize the disability process. We support these efforts and would like to see greater accountability from the Office of Hearings and Appeals in reducing processing times and increasing the number of completed hearings.

The agency is meeting the commitments made to you and to this committee on its 800 number telephone service. However, SSA does not offer the same service to the public who call local offices. Almost all managers feel their offices are giving poor service to the calling public. This is the number one complaint heard in your offices. We urge you to appropriate sufficient funds to allow the agency to provide world-class telephone service to those who choose to call their local offices.

The issues I have outlined are important to the American people. It is vital that SSA have the resources to provide services that Americans have paid for, deserve, and expect.

Thank you again, Chairman Porter, for the opportunity to testify at this time, and I would be happy to answer any questions.

[The prepared statement of Ron Neising follows:]

[Pages 249 - 255--The official Committee record contains additional material here.]

Mr. Porter. In the course of your testimony, Mr. Niesing, you said, if I am correct, that less than half of the employees of Social Security have public contact.

Mr. Niesing. That is correct. About 28,000 out of the 65,000 actually work in the offices that are in our communities across the country.

Mr. Porter. Can you tell me what the rest do, generally?

Mr. Niesing. Many of them work in our headquarters complex, in our processing centers. They are located in seven sites across the country.

Mr. Porter. Data processing?

Mr. Niesing. Right.

Mr. Porter. Okay. Well, we appreciate very much your testimony today. Obviously, this is a very important subject. It is the place probably where more of our citizens contact government than any other, and obviously we want to do the best we possibly can and give you the resources you need to do your work. Thank you for your statement.

Mr. Niesing. Thank you

Wednesday, January 28, 1998.

WITNESS

BRUCE M. CHRISTENSEN, AMERICAN SOCIETY OF TROPICAL MEDICINE AND HYGIENE

Mr. Porter. Bruce M. Christensen, M.D., Chairman Legislative Task Force, representing the American Society of Tropical Medicine and Hygiene.

Dr. Christensen.

Dr. Christensen. Thank you.

Mr. Chairman and members of the committee, I am Director of the Tropical Disease Research team at the University of Wisconsin, and I am appearing on behalf of the American Society of Tropical Medicine and Hygiene. This is a professional society composed of 3,500 researchers and medical practitioners who are devoted to addressing the global threat of infectious diseases. A strong U.S. research agenda on infectious diseases is critical at this time when the ease of travel and openness of trade exposes the world's population to new and reemerging infectious disease agents.

Mr. Chairman, we thank you for your strong support for this agenda and your continuing commitment to provide funding that will sustain our research infrastructure in the years to come.

You have my written testimony. What I want to try to do is highlight a few of the things that we feel are the most important concerns.

From fiscal year 1993 through 1998 the National Institutes of Allergy and Infectious Diseases received 40 percent funding increases for their extramural programs, but the research management and support budget increased by only a tenth of 1 percent. Our society is concerned that we are not providing the Institute with the resources necessary to manage our important infectious disease research programs.

We are not arguing for large increases, but merely calling for responsible stewardship of the extramural programs and grants to ensure that we are effectively meeting the appropriate goals and objectives.

The Society also applauds Dr. Varmus and Dr. Fauci for their leadership at home and abroad in advancing the multilateral initiative on malaria and for implementing the Institute's research plan for malaria vaccine development. Malaria has reemerged as one of the world's most serious diseases, causing approximately 500 million clinical cases and 2 to 3 million deaths each year. The tragic thing is that the majority of the deaths occur in African children under the age of 5.

Malaria is a complex disease and its control will require significant research effort. We are pleased that NIH recognizes this and is willing to commit significant resources towards solving the problem, and we urge the committee to be supportive as well.

Two Institute programs have been critical in advancing our understanding of tropical diseases, and our Society urges the committee to not only continue these programs but to increase support for these important projects. They are, first, the International Collaborations in Infectious Disease Research grant program that supports collaborative research between U.S. investigators and foreign institutions in countries where these tropical diseases are endemic; and secondly, the Tropical Disease Research Unit is a domestic grant program that promotes

the application of modern technologies to the development of new vaccines, drug therapies or methods for vector control of tropical parasitic diseases.

The Society also appreciates the committee's support for funding increases in fiscal year 1999 for the CDC's emerging and reemerging infectious disease program. We strongly encourage the committee to support CDC's infrastructure, which include the need for new bio containment laboratories in Atlanta.

The real need for this is illustrated by the recent outbreak of avian influenza in Hong Kong, when CDC laboratories actually had to reduce research on certain pathogens to make room for this new pathogen. Space limitations that require the cessation of research activity of one pathogen to make room for another is a dangerous situation that must be addressed immediately.

As the 20th century comes to a close, I think we must remember that infectious disease agents have no respect for political or geographic boundaries, and social or economic status do little to ensure safety from new diseases or those reemerging as a consequence of drug resistance or other causes.

I spend some of my time working with lymphatic filariasis in village populations on the Nile Delta, and many other members of our Society work in the tropics where the vast majority of the world population resides.

Mr. Chairman, if we turn our backs on the health threats to the growing majority of people living in the poorly sanitized areas of this planet, I truly fear an erosion of this Nation's humanity and world leadership. I trust you share these concerns, and I want to emphasize again that we sincerely appreciate your past support of these activities and urge you to continue your efforts to double the NIH budget over the next 5 years.

Towards this end, we obviously, as every other group here, will probably recommend a 15 percent increase in the NIH budget for fiscal year 1999. We also request that the committee provide a $15 million increase for the CDC's emerging infectious disease activities.

I thank you for this opportunity to talk to you.

[The prepared statement of Bruce Christensen follows:]

[Pages 259 - 269--The official Committee record contains additional material here.]

Mr. Porter. Dr. Christensen, just one short question.

You said that you coordinate your efforts or work directly with institutions of countries in the tropics where these diseases are most prevalent.

Mr. Christensen. That is the one program project grant.

Mr. Porter. Which would be a leading country to have that kind of research institution, Brazil?

Mr. Christensen. Well, there are projects that in the past and presently go on in Brazil, in Thailand, in Kenya, in Sudan, in Malawi, in Mali.

Mr. Porter. But do they have research institutions like

ours?

Mr. Christensen. Yes, they do.

Mr. Porter. In those countries?

Mr. Christensen. I would not say they are ``like ours,'' and that is where there is a collaboration between U.S. institutions and these institutions. It benefits both ways, because it brings technology to them in new ways of looking at things, but it gives the U.S. scientists a real appreciation for the problems that are at hand there. That is why they are so critical, especially when diseases now are sort of flying around the globe at a pretty rapid rate.

Mr. Porter. Thank you very much for your good testimony.

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WITNESSES

ALISON RUMERY-RHODES
JUDITH S. JACOBSON, SUDDEN INFANT DEATH SYNDROME ALLIANCE

Mr. Porter. Alison Rumery-Rhodes, Sudden Infant Death parent, testifying in behalf of Sudden Infant Death Syndrome Alliance.

Mrs. Rumery-Rhodes. Mr. Chairman and members of the subcommittee, my name is Alison Rhodes, and this is my husband, Kenny.

Until August of 1997, my husband, Kenny, and I felt we lived a charmed life. In a matter of a few hours, our lives and our innocence were destroyed. On April 12, 1997, I gave birth to a beautiful boy named Connor Andrew Rhodes. Nothing compared with the sheer ecstacy of holding my newborn son. Kenny and I felt our lives were complete.

After 10 weeks, I returned to work and carefully selected a small day care facility that was run by a family. There was never a day I worried about the care he was receiving.

Tuesday, August 5, started out like any other day. One of the images that is the most vivid and unforgettable is Connor sitting in his carrier and smiling as I kissed him good-bye.

My morning was busy, as usual. After coming out of a meeting, my phone rang. It was Jenny from day care saying the words I will never forget, ``There is a problem with the baby. He is not breathing.''

After that, I remember hearing myself screaming, ``Oh, my God.'' As I raced to the hospital, I was already making deals with God, ``Take me; just save my baby.''

I can't imagine the hell my husband went through that morning as he reached day care. He saw the paramedics trying to revive Connor. He felt powerless and unable to protect his son. Kenny knew, even then, that Connor was gone.

When I reached the hospital, I believed I was going to find Connor alive. Then I heard the words that haunt me still, ``He is with God now.'' I heard myself screaming louder than I ever knew possible.

They took us to see our precious angel, who seemed to be peacefully sleeping, and I begged him, ``Just please open your eyes, sweetheart,'' but he never did.

The next day, we learned that an insensitive social worker

had the day care family interrogated at police headquarters and threatened to shut down the facility. I immediately called them, offering my support and assurances that I didn't hold them responsible. The community, however, was not as forgiving.

Mr. Chairman, while a standardized Death Scene Investigation Protocol for SIDS was created by the Centers for Disease Control and Prevention, it is not implemented consistently. I urge the committee to ask every State to implement this policy. It would help to end this type of harassment of the grieving.

Our pediatrician told us that Connor's death was most likely due to SIDS. It had never occurred to me that we would be one of its one-in-a-thousand victims. Little did I know that most SIDS babies, like Connor, appear to be perfectly healthy.

We soon decided that we wanted to learn as much about this disease as we could and help find a cure. We were put in contact with the SIDS Alliance, who I am speaking on behalf of today. They helped us immensely and taught us many things.

One infant an hour dies of SIDS. It is neither preventable nor predictable. It is the leading cause of death amongst infants one month to one year of age, and certain risk factors have now been identified.

The U.S. ``Back to Sleep'' campaign led by the National Institute of Child Health and Human Development has resulted in a 38 percent decrease in SIDS, the highest reduction in infant mortality in 20 years. But this is not the only answer, and further funding is still needed to understand SIDS and discover a means of prevention.

While nothing will take away the grief and emptiness my husband and I feel, we have made a commitment to do everything we can to save children at risk. Connor will not die in vain. We are expecting our next child in July, and while this will be a joyous occasion, it will never ease the pain we live with every day.

On behalf of Connor and all other SIDS babies, I urge you to increase the fiscal year 1999 appropriation for the National Institute of Child Health and Human Development to $775,980,900, an increase of 15 percent; and a down payment on doubling the NIH budget. A 15 percent increase would allow NICHD to begin to fulfill the goal of doubling SIDS research over the same period of time.

We also urge this subcommittee to continue funding for the SIDS Resource Center at the Health Resources and Service Administration and the SIDS Death Scene Protocol Initiative at the Centers for Disease Control.

I thank you for your time and support and welcome any questions.

[The prepared statement of Alison Rumery-Rhodes follows:]

[Pages 273 - 279--The official Committee record contains additional material here.]

Mr. Porter. Mrs. Rhodes, what was the recent development that I have read about and that you alluded to that had to do with SIDS, and it looked like there was some real progress

being made?

Mrs. Rumery-Rhodes. There is definitely real progress being made. However, it is not the only answer. One of the risk factors is considered prone sleeping, but Connor is a perfect example, he was on his back and he still died.

Yes, there is a tremendous amount going on, but we see the end.

Mr. Porter. I read in the last few weeks somewhere that there was something else that had been identified as a prime suspect at least in SIDS.

Mrs. Rumery-Rhodes. I am not aware of it. I don't know.

Mr. Porter. But I could be wrong.

Mrs. Rumery-Rhodes. Judy probably knows.

Ms. Jacobson. I am Judy Jacobson. I am with the SIDS Alliance.

There have been all sorts of risk factors that have been identified from time to time. The most recent study, coming out of New Zealand this morning, showed something about caffeine being linked with an increased risk for SIDS.

We know that cigarette smoke obviously is something that has a definite impact. In addition to the sleeping on their stomachs, the other recommendation that we do make is that infants be kept in a smoke-free environment, that parents get good prenatal care and that all of the things that would impact a pregnancy, whether they be caffeine, nicotine or any type of drug or alcohol abuse would certainly be something we would discourage.

Mr. Porter. It might have been caffeine that I saw, and I must have seen it this morning.

Ms. Jacobson. It just came out.

Mrs. Rumery-Rhodes. It was this morning.

Mr. Porter. I recall reading something recently. That must have been it.

I wish I could say something that would give you comfort in this. The only thing I can really say is that Dr. Alexander places this at a huge priority, as you know, and so do we, and we will do everything we can to get him the resources that he needs to find the breakthrough that will end this, and we will do our best.

Mrs. Rumery-Rhodes. Thank you very much.

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WITNESS

WALLACE E. ZEDDUN, UNITED DISTRIBUTION COMPANIES

Mr. Porter. Wallace E. Zeddun, vice president, Wisconsin Gas Company, representing the United Distribution Companies.

Mr. Zeddun. Mr. Chairman, thank you very much for the opportunity to testify. I represent the United Distribution Companies today, a coalition of Northeast and Midwest local distribution utilities; a list of which is attached to my testimony. Those companies and my own have a very strong commitment to seeing that the energy needs of the disadvantaged in this country are being met.

What we are requesting for fiscal year 1999 for the Labor-

HHS appropriations bill is a return to the funding levels of $1.319 billion, to provide for advanced appropriations of $1.319 billion for fiscal year 2000, and to eliminate the setaside for the leveraging incentive program.

We believe that this is appropriate for the following reasons in my prepared testimony but three of which I would like to highlight. One, the need still exists; two, this is a key program to support welfare reform; and, three, it is also a foundation program to allow low-income customers to reap the benefits of deregulation in the future.

Starting with the first one, the need still exists. The Center on Budget and Policy Priorities, in a recent report using current census data, indicated that the average income for the poorest 20 percent of families in this country actually fell 1.8 percent from the time period 1989 through1996. The poverty rate in 1996 was 13.7 percent as compared to 13.1 percent in 1989. Now, that is also a much larger population base, so it compounds.

The percent of families having children and elderly who live in poverty is roughly the same in 1996 as it was in 1989. During this same time frame, energy prices have increased moderately. However, on the other hand, this program has been cut over 30 percent during this same time frame. When you combine income stagnation for the impoverished along with increasing energy prices and a significant decrease in energy assistance, the inescapable conclusion is that the energy burden is as great now as it was in 1989, if not greater.

My second point, welfare reform. Energy assistance was one of those programs designed not to be solely a welfare program. It was designed to be a supplemental assistance program for the working poor. That is essentially what is happening with welfare reform.

We all agree with the laudable goals of trying to get as many people working as possible. What we find in our community, as far as welfare reform, is that the citizens who are engaged in the program are being employed at average wages ranging from $6.59 to $7.56. This means they still qualify for this program. On the other hand, they lose their access to food stamps, and that is being borne out by Catholic Social Services. They are seeing a doubling, many more people coming to their food kitchens who are participating in welfare reform, and they also lose access to Medicare.

These families need to rebuild their credit histories; they need to rebuild their work histories.

If we remove the supplement, energy, which is one of their largest burdens, it may very well be the crushing death that does not allow them to rebuild their credit histories and thus have no chance to participate in the future to get higher paying jobs as they rebuild their work history. For that reason, I submit that this should be viewed as a bridge program for people who are in welfare reform.

Deregulation: My business--our industry is being deregulated. My company will be a transporter essentially under deregulation. Private companies, nonregulated, will sell the gas molecules. I think you only need to ask a few questions to see the impact.

If you are a private company, who are you going to be competing for, somebody who lives in the suburbs where the

ability to pay is high, or a business or somebody in the central city, where you have a high uncollectable problem? Which customer class will get the best terms, the best conditions, the best prices? Which customer classes have the most clout, the most influence?

This is a foundation. Without this foundation, the poor will not be able to afford to pay their energy bills. They will not be able to participate in receiving the most favorable benefits under deregulation.

For this reason, I urge the committee to support energy assistance as it has a key role in supporting welfare reform and in making sure that the deregulation benefits go to all families. I thank you very much for your consideration.

[The prepared statement of Wallace E. Zeddun follows:]

[Pages 283 - 291--The official Committee record contains additional material here.]

Mr. Porter. Mr. Zeddun, I think that is probably the best case that can be made for it.

How do you answer critics, like myself, who say this is a Federal program that was instituted at the time of the Arab oil embargo, the second Arab oil embargo, when fuel prices were very high and today fuel prices in real terms are lower than they were then? And if this isn't a Federal program that ought to be terminated because the reason for its existence has disappeared, what is?

Let me say, I recognize the need. There are people out there that are in need, there is no question about it. But is this the way to address it on a program whose rationale, in my judgment, has disappeared long ago?

Mr. Zeddun. I think if you focus only on energy prices, you would have to give serious consideration to it. But you have to look at the other side of the equation, which is the spending power of the families.

If you go back and if you do the work and look at the statistics, the burden that families have when this program was created is largely unchanged, because their incomes haven't kept up. Energy prices have gone up, and have moderated since 1989, but the incomes of the poor haven't kept pace with inflation, so the burden has gone down. It has remained roughly the same so the need is still there.

As with any poverty program, the broader you spread it, the less it costs all citizens of this country.

Mr. Porter. Well, the problem of poverty and welfare existed before this program. Somehow, the energy companies were mandated, probably by the States, not to cut off supplies of energy to customers during times that would threaten their health, whether it is extreme cold or extreme heat.

There are those who see this simply as a program that helps utilities handle their otherwise bad debts and not a program that should be addressed through this way, it should be addressed through welfare, through direct payments to families. What do you say to that? I am not going to get you into a long debate on this.

Mr. Zeddun. Right. I think to recognize we have bad debts, but they are not our bad debts, they are customer bad debts. And go back again, because the moratorium does not relieve the obligation to pay, it only says we cannot disconnect. It doesn't say that the customer doesn't owe the money.

That means without the supplement, the debt load gets higher. Bankruptcies, as we all know, are escalating at a rapid pace and becoming a very endemic problem in this society. So I think if you look at the broad impact, that iswhere this becomes a very important program.

Mr. Porter. That is not our job, but I think the authorizing committee ought to relook at this program entirely, target it better, change the nature of the program, and not continue it in its present form. But that is simply where you and I differ.

To me, it is kind of an example of how you start a program and it goes on forever. We have had great difficulty in addressing, I think, priorities, because obviously the program has a need and it has a strong constituency and it probably will go on. But I would like to see it go on at least in a form that has a greater rationale for the real problem that it addresses, and that is the problem of poverty and not high energy costs.

Mr. Zeddun. It is really a combination of the two. I mean, that probably is the biggest change the program has made in the last several years, is that as opposed to just looking at it from a poverty perspective, because there are people who are low-income who can afford to pay all of their bills. I mean, let's not make the assumption that every low-income family needs this program. That is not true. There are people who live in very substandard housing with very high energy bills and have very low incomes, and that is the targeting that has really happened over the last several years to make this program more effective, and it had to because of the cuts.

I mean, in the past when it was funded much higher, initially it was run more like a welfare program. It is now being run based on trying to determine which households really have the greatest need for the program.

Mr. Porter. Well, to be continued.

Mr. Zeddun. Yes.

Mr. Porter. Thank you for your testimony.

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WITNESSES

ALAN BROWNSTEIN, AMERICAN LIVER FOUNDATION
DEBBIE DELGADO-VEGA

Mr. Porter. Alan Brownstein, president of the American Liver Foundation, testifying on behalf of the Foundation.

Mr. Brownstein. Good afternoon.

Mr. Porter. Good afternoon.

Mr. Brownstein. Mr. Chairman and members of the subcommittee, my name is Alan Brownstein, and I am the president of the American Liver Foundation. I am joined here today by Debbie Delgado-Vega who is the president and founder

of the Latino Organization for Liver Awareness.

I want to thank you for giving us this opportunity to testify.

First, we must thank you for your past leadership in support of biomedical research overall and specifically for liver disease. This year, unlike previous years, thanks to the work of this committee, I have some important progress to report. This progress will help benefit the research community in helping to fight liver disease, because there are now two historic documents that have been produced.

First, we have the Hepatitis Consensus Development Conference that was sponsored by NIH last March that has made significant recommendations as to the appropriate research and public health response needed for hepatitis C.

As the committee knows, hepatitis C has been classified as an emerging infectious disease, and the death rate from the disease each year is now at 10,000 and will more than triple by the year 2010 unless there are significant interventions that occur.

The second document and one that was requested by this subcommittee presents the collective wisdom of 13 NIH Institutes on the research necessary to meet the challenges of liver disease. This, in fact, is the first ever research agenda to fight hepatitis and other liver diseases, which is near completion and will be submitted to this committee in the very near future. We thank Dr. Gordon and Dr. Hoofnagle at NIDDK for their leadership in producing this document.

We hope the subcommittee will consider these two documents as you fix your appropriations for this year.

However, in addition to research, education of the public, patients, and physicians is essential to prevent hepatitis and other liver diseases, and while national leadership is needed, what is more important is the grass-roots efforts that provide people with the health information that they need to know to help prevent diseases. ALF has chapters to do this throughout the country. We have also formed an alliance with the American Digestive Health Foundation and we will be convening a national summit here in Washington on February 24th, where we will be bringing together national organizations and local organizations from all over the country to address hepatitisand to provide that education that is needed.

A model of one of those grass-roots organizations is the Latino Organization for Liver Awareness. We have Debbie Delgado-Vega with us today, who herself has received a liver transplant. A concrete example of how these organizations can work is that organ donor awareness--and we know how badly that is needed--that the consent rate among Hispanics in New York City was 30 percent in 1993.

LOLA, Latino Organization for Liver Awareness, was formed in 1994, and over the 3 years since LOLA has existed, that consent rate has gone up to 59 percent, a 29 percent increase. So, therefore, that is a concrete example of how grass-roots organizations can work.

Now it gives me pleasure to introduce Debbie Delgado-Vega to share a little bit more about that.

Ms. Vega. Thank you, Mr. Chairman, for giving us the opportunity for being here. Again, I would just like to repeat,

my name is Debbie Delgado-Vega and I am the founder and chairperson of the Latino Organization for Liver Awareness--we like to call it LOLA--in New York City. I am also a liver transplant recipient.

Back in April of 1992, at the age of 29, I was diagnosed with border immune hepatitis, an incurable liver disease. My liver had generated into a mass of scar tissue. My only antibodies were attacking my liver, as it was foreign. My only chance for survival was a liver transplant.

All I knew about hepatitis was that it was something contagious and that cirrhosis was alcohol related. My ignorance embarrassed me. In fact, my liver disease was not contagious, it was generic. My life stopped, but only for a minute.

Devastated but not beaten, I went on a mission in search of information about my illness, and I learned that there were about 100 different liver diseases and that an estimated 60,000 people await organ donation in the Nation. I realized that information and support for the Hispanics suffering from liver disease and those in need of a transplant was needed. This led me to take action, and I created LOLA, the Latino Organization for Liver Awareness, the first organization of its kind in the country. That was in 1994, one full year before my own transplant, before my own miracle of life.

Since then, LOLA has touched many and saved many lives of Latinos who otherwise would have not received the proper treatment or care. What brings people like LOLA and the American Liver Foundation together is our love of life and the community. And together we can transform our individual struggles into a collective movement to fight for life.

Thank you.

Mr. Porter. Thank you both for testifying. We certainly share your concerns and will do everything we can to provide the kind of funding that makes a difference.

Thank you.

Mr. Brownstein. Thank you very much, Mr. Chairman.

Ms. Vega. Thank you, Mr. Chairman.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[The prepared statements of Alan Brownstein and Debbie Delgado-Vega follow:]

[Pages 296 - 303--The official Committee record contains additional material here.]

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WITNESS

VINCENT J. BUFALINO, M.D., AMERICAN HEART ASSOCIATION

Mr. Porter. Vincent J. Bufalino, M.D., director of cardiology at the Edward Cardiovascular Institute and president of the Midwest Heart Specialists, testifying on behalf of the American Heart Association.

Dr. Bufalino.

Dr. Bufalino. Thank you, Mr. Chairman.

I am a practicing cardiologist in suburban Chicago and a member of the National Board of the American Heart Association. I am here today to talk to you about heart attacks, strokes, and other cardiovascular diseases, still America's number one killer, the leading cause of disability in our country.

Cardiovascular disease accounts for nearly one of every two deaths in the United States. Chances are, heart attack, or stroke, will be the death or disabler of you or someone you love.

The American Heart Association commends your championship of the NIH and the CDC, but we are concerned that insufficient resources are being devoted to research and prevention of this, America's number one killer, heart disease, the number three killer, stroke, and it is clearly the most disabling.

Now is the time to capitalize on the progress in understanding heart attack and stroke. Promising, cost-effective breakthroughs are on the horizon. Theseinitiatives will reduce health care costs and improve quality of life for all Americans.

We urge you to take three steps for fiscal year 1999. Appropriate a 15 percent increase over current funding for the NIH, the first step toward doubling the budget in 5 years. This goal is echoed by Research America, as you know, and the Ad Hoc Group for Medical Research Funding.

Secondly, provide a 15 percent increase over fiscal year 1998 funding, specifically for NIH heart research and stroke research. And thirdly, appropriate $21 million for CDC's Cardiovascular Health Program.

Thanks to the advances in treatment and progress and learning about risk factors, more Americans are surviving heart attack and stroke. No longer do heart attack or stroke necessarily mean immediate death. But now they can mean permanent disability, requiring costly medical care, loss of productivity, and, of course, decreased quality of life. We still have much to do.

Heart and stroke researchers are on the brink of advances that could pave the way to the cure or least prevention, but these studies need more funding. Research has produced the first effective emergency treatment for stroke. The clot-buster drug T-PA can stop a stroke in progress and reduce permanent disability when used within 3 hours.

T-PA could be a miracle drug. It could benefit an estimated 450,000 Americans at risk of a clot-causing stroke each year. But, again, this is not happening. Too often, people do not recognize stroke symptoms, patients are not getting to the hospital on time, and many health care providers don't treat stroke as an emergency.

Moreover, patients would benefit from improving imaging capabilities so that we could make the diagnosis quickly in emergency settings.

In order for T-PA to live up to its full potential and find new ways to fight stroke, funds must be invested in cutting-edge research. Heart attacks and half of all strokes are the result of arteriosclerosis. This is the disease process that obstructs blood vessels. New theories about the origins of

arteriosclerosis are emerging. One is inflammation of a blood vessel wall; another, a common viral infection; a third, the presence of an inherited defective gene.

Imagine taking an antibiotic or a vaccine and preventing a heart attack or a stroke. More funds are needed now, because these studies may revolutionize the way we prevent or treat a heart attack or a stroke. Results could help prevent the estimated 1,000,000 heart attacks and over 600,000 strokes that Americans suffer from each year in this country.

You probably know someone who suffers from congestive heart failure, the most common cause of hospitalization for those over 65 in America. This disabling condition is growing because, thanks to research, more and more people are living longer, but with damaged hearts, only to be inevitably limited by congestive heart failure.

Congestive heart failure is a horrible disease. For many, relatively simple tasks like making a bed or preparing breakfast can be so fatiguing that they need to spend the rest of the day in bed. Some must rely on constant daily oxygen. A heart transplant may be the only way to curtail their suffering or postpone death for some patients, but, as we know, donors are quite scarce.

Funds to study promising areas, including removal of nonfunctioning heart muscle, new electronic devices to drive the heart, could mean a new lease on life for the 5 million Americans who suffer from congestive heart failure.

Most people do not associate children with heart disease. Heart defects are the most common birth defects, 23,000 each year, a key cause of childhood disability, and in fact over 20,000 will die before their first birthday.

Scientists often do not know why these defects occur. But questions are being answered through the work of the Specialized Centers for Research of Pediatric Cardiovascular Diseases known as SCORES. Resources to renew these SCORES will allow continued progress in the fight against these conditions that can severely restrict quality for life of newborns, children, grandchildren.

Research results must find their way into the communities where heart attack and stroke inflict their damage. The CDC works to build that bridge from the lab to the community. The strength of that bridge has been enhanced by the creation of the CDC Cardiovascular Health Program. Thanks to your help, beginning this year, as many as 5 States will receive funds to begin this comprehensive disease prevention and control program.

We advocate an appropriation of $21 million to continue to reach out to States on heart disease and stroke prevention. Increasing resources for both research and community intervention will allow us to take great strides against heart attack, stroke, and other cardiovascular diseases. This could mean the difference between life or death for many of us or someone we love.

Thank you, Mr. Chairman.

[The statement of Vincent J. Bufalino, M.D. follows:]

[Pages 307 - 318--The official Committee record contains additional material here.]

Mr. Porter. Dr. Bufalino, I do know someone who had congestive heart disease, and that was my mother, who died of congestive heart failure. So I am very familiar with the condition.

You said something that I didn't quite understand, and you said that often health care providers don't treat stroke as an emergency. Is that what you said?

Dr. Bufalino. I did. It is interesting; stroke has been thought of as a permanent disabling disease; when it happened, there was really nothing that could be done. Once it had occurred, it was complete; much like heart attacks were 15 years ago when we really didn't have much to offer folks. They would come in, we would put them in intensive care and then we would wait for the complications.

Stroke was very similar. This new onset of new therapies where we can actually go in, dissolve a clot and actually return full function to a paralyzed arm or leg, so that information is clearly new, a part of the educational process that needs to be done for emergency physicians, neurologists, and anyone else who is taking care of stroke patients.

Mr. Porter. So that education process isn't necessarily complete at this point in time?

Dr. Bufalino. Absolutely not. It is something that we are actually in the middle of tackling now. The American Heart Association is actually taking the lead to send these kinds of information out to practitioners across the country, in rural areas, where these drugs can be easily administered.

Mr. Porter. Well, thank you very much for your testimony. It is good to see a fellow Illinoisan here. And I learned a lot listening to you.

Dr. Bufalino. Thank you, sir. Thank you for your time.

Wednesday, January 28, 1998.

WITNESS

C. MICHAEL SAVAGE, SINAI FAMILY HEALTH SERVICES

Mr. Porter. C. Michael Savage, Chief Executive Officer, Sinai Family Health Services, testifying in their behalf.

Dr. Savage. Thank you, Mr. Chairman, for providing Sinai Family with the opportunity to present testimony before your subcommittee this afternoon. I feel a little bit like a fish out of water. I am a health care provider, not a researcher, so I am going to speak to those issues.

As the Chief Executive of Sinai Family Health Centers, we are the largest network of community health centers in the Chicago area. We were born out of Sinai Hospital in the 1980s, and it was awarded federally qualified health center status in 1991. We currently have 23 sites, and we have approximately 170,000 visits a year by about 60,000 patients.

As you are probably well aware, the 1990 census figures show that seven out of ten of the poorest communities in this country are in Chicago. We have facilities in five of those

communities, serving the indigent, the unemployed, and the working poor, regardless of their ability to pay.

Sinai Family's vision for the health future of its patients is focused on a plan to develop a system of urban community health care. In order to maintain this commitment, we continually reassess and respond to the rapidly changing health care environment. As you know, over 41 million Americans today are uninsured, the largest amount since the enactment of Medicare and Medicaid. Community health centers fill a critical void by providing care to over 10 million of those persons.

In Cook County, Medicaid rolls have decreased by 60,000 in the last 2 years. While this is good news--and much of it due to a rapidly improving economy, as well as changes in the welfare and immigration laws--there is also a down side. The vast majority of those 60,000 individuals, primarily women, and children are now also uninsured, even though their parents work.

Similarly, with increased enrollment of Medicaid patients in managed care, community health centers throughout the country are receiving decreased reimbursements for serving managed care patients.

Even though Sinai Family has reengineered its service delivery systems and cut encounter costs by 22 percent, we, like other community health centers, are being squeezed financially by reduced levels of reimbursement and increased numbers of uninsured persons.

For these reasons, Sinai Family is pleased that the National Association of Community Health Centers is working with Congress and the administration to secure a $100 million increase in the Consolidated Health Center Program to serve 350,000 more uninsured persons.

Sinai Family has also been pleased to be given a recent opportunity to work on reducing infant mortality rates and low birthweight rates on Chicago's Westside through a Healthy Start grant. Nineteen out of every 1,000 babies born in Chicago's Westside die during their first year of life. Through this Bureau of Maternal and Child Health Healthy Start grant, we will be able to reduce this shockingly high rate of infant mortality and low birthweight rates through the implementation of proven community health practices.

We have also developed a number of programs to respond to other health care needs of low-income residents in Chicago's poorest neighborhoods. A more detailed description is in my written testimony, which has been submitted, but three I want to mention briefly.

Senior citizens, even though they are insured with Medicare, we are finding, are having tremendous health problems in the inner city. That is not only a combination of aging but also poverty and fear of crime, which limits people's ability to both access and stay attached to primary health care.

In the last 4 months, through a senior outreach program, we have linked 400 seniors with chronic health care problems to ongoing primary health care. I would encourage you to ask the Administration on Aging to develop some evaluation programs looking at these linkage types of programs.

Likewise, the CDC should continue its work to control the spread of HIV and other sexually transmitted disease. Thereis

now strong evidence that the presence of other STDs increases the likelihood of both transmitting and acquiring HIV and that, conversely, early identification and treatment of STDs can slow the spread of HIV.

Lastly, despite overall lower rates of breast and cervical cancer among African-American women, we are seeing all sorts of research that shows that they have a higher mortality rate because their illness is diagnosed later in their disease. Sinai would welcome the opportunity to work with the CDC to expand early screening and treatment programs to address their specific needs.

Mr. Chairman, I would like to thank you for your past support for the community health center program and for the opportunity to present testimony this afternoon. I would be happy to answer any questions on health centers in your hometown.

[The prepared statement of C. Michael Savage follows:]

[Pages 322 - 329--The official Committee record contains additional material here.]

Mr. Porter. My hometown? Chicago isn't quite my hometown, but it is close.

Mr. Savage. The Chicago metropolitan area, how is that?

Mr. Porter. You mentioned that the Sinai Family Health centers are in the process of developing a system of urban community health care. Can you expand on that a little bit?

Mr. Savage. As you probably are well aware, in more middle-class or affluent communities, you have a primary health care infrastructure. You have private physicians, you have group medical practices, you have staff-modeled HMOs. In most poor urban communities and in many rural communities, that infrastructure doesn't exist outside of community health centers and hospital emergency rooms. Private practices have essentially left those communities, if they have ever been there.

So I think the community health center program is central to putting primary care infrastructure into communities. I think that is why NACHC's request is so important, because if that infrastructure is not there, there is no way to deliver health care in a cost-effective manner and also in a continuous manner.

But even with that infrastructure, I really believe that there have to be other programs like some of the ones that I have mentioned that target particularly vulnerable groups of individuals or particular diseases in order to keep people successfully attached. So that is what I am trying to speak to.

Mr. Porter. Mr. Savage, thank you very much for your good statement. We will also do our best in respect to your concerns.

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WITNESS

THOMAS M. BRUCKMAN, UROLOGIC RESEARCH AND CARE COALITION

Mr. Porter. Thomas Bruckman, Executive Director and CEO of the American Foundation for Urologic Disease, testifying on behalf of the Urologic Research and Care Coalition.

Mr. Bruckman. Good afternoon, Mr. Chairman, and thank you.

I am Tom Bruckman, CEO of the AFUD, and also Director of Public Policy of the National Prostate Cancer Coalition. I am here today speaking on behalf of the Urologic Research and Care Coalition, and we would like to begin by thanking you for your support of biomedical research at NIH and throughout the government.

However, Mr. Chairman, despite the efforts of Congress to fund urologic research, the program continues to fall behind other areas at NIH. While Congress approved a 7.5 percent increase last year, the NIDDK within the Institute chose to limit urology to 3.5 percent instead of the 7.5 percent. The growth of spending for urology at NIH was among the lowest of all categories; only research into lead poisoning received a smaller increase. We understand the NIH recently committed to increase urology funding at the same rate as the overall funding rates, and we appreciate that, but it is a little bit behind at this point.

Mr. Chairman, the number of Americans who suffer from urologic diseases and conditions is staggering. The NIH estimates that every year over 8 million people suffer fromacute urinary conditions, such as urinary tract infections. Over 4 million people experience bladder disorders. Approximately 13 million adults suffer from incontinence. Interstitial cystitis affects nearly 500,000 people. More than 2 million men will experience prostate disease, the most diseased organ in the human body, like BPH or prostatitis. Over 200,000 new cases of prostate cancer were diagnosed and over 40,000 men died last year.

Thousands of people are diagnosed with kidney, bladder, and testicular cancers. Approximately 15 to 20 million men over 40 suffer from impotence. The estimated economic impact of urologic diseases and conditions exceeds $50 billion a year. For fiscal 1999, the Coalition recognized an overall increase in urologic research funding of 9 percent.

We also recommend the subcommittee take steps to address the disparity of funding for prostate cancer research, specifically. The NCI should be able to commit at least 100 million for research for fiscal year 1999. The URCC also recommends that the subcommittee direct the NCI to put research funding on breast and prostate cancer into equilibrium as quickly as possible. Almost 50 percent of all cancers in the human body occur in the urologic tract.

The Coalition believes that the disparity in urologic research funding is due in large part to the lack of focus for urology research at NIH and within the Federal Government generally. Traditionally, grant applications in urology have been sent to as many as nine Institutes at NIH, with possible review by 20 study sections.

The NIH has finally responded to some of these concerns by creating a special emphasis panel to review urologic research grant applications. The panel is designed to ensure that appropriate urological expertise is available for grant review, but it is just being set up, and it is a long time in coming.

Just yesterday, the NIH expressed its willingness to work effectively on this particular issue. We ask the subcommittee to make sure that they continue this effort.

The problem caused by having nine institutes in the mix is compounded by the addition of other Federal agencies, such as the VA, the CDC, and the DOD now funding some portion of urological research. In order to maximize the effectiveness of all of these efforts, a strong steering committee needs to be in place. The present coordinating council does not have the budget or the authority to be effective.

The Coalition recommends three steps to improve the structural problems facing federally funded urologic research: Number one, focus urologic research in fewer Institutes; review the number of study sections reviewing urologic applications; strengthen the role of the interagency council in urology by giving a budget and clear authority to coordinate federally funded urologic research activity.

The subcommittee called last year on the NIDDK to develop a urologic disease database, something we presently don't have. We urge the committee to make sure that the NIDDK continues its efforts to complete this work soon.

Lastly, let me mention URCC's concern that the NIDDK has just scratched the surface on activities relating to women's urologic health programs.

Mr. Chairman, that completes my testimony. My entire testimony is available in written format.

[The prepared statement of Thomas Bruckman follows:]

[Pages 333 - 339--The official Committee record contains additional material here.]

Mr. Porter. Mr. Bruckman, you are right on time. You are, I am sure, aware that this particular subcommittee has a great concern about prostate cancer. We lost two of our prominent Members, George O'Brien and Sil Conte, to prostate cancer.

Mr. Bruckman. Yes, sir.

Mr. Porter. I think we have made it a priority.

You also know that we don't fund by disease, we fund by Institute. When you find yourself spread among a lot of Institutes, it is hard to----

Mr. Bruckman. It is part of the uncoordinated factor.

Mr. Porter. It is what you were talking about.

Mr. Bruckman. Yes, sir.

Mr. Porter. We certainly do place urological research at a high priority, and we do, I think, send clear messages to NIH of our feelings in that regard. So we will do our best to respond to these needs. I think they are real and, overall, the decisions on where scientific opportunities lay has to be with science and not with this subcommittee, obviously.

On the other hand, I think the suggestions you have made about strengthening the panels and making certain that the peer review process works fairly in respect to diseases like prostate cancer and other urological ailments is a very real problem that I think NIH is attempting to address. We will keep our eye on it.

Mr. Bruckman. Thank you, sir, we appreciate your support. That is very encouraging. Thank you.

Wednesday, January 28, 1998.

WITNESS

STANLEY B. PECK, AMERICAN DENTAL HYGIENISTS' ASSOCIATION

Mr. Porter. Stanley V. Peck, Executive Director, American Dental Hygienists' Association, testifying on behalf of the Association.

Mr. Peck, nice to see you again.

Mr. Peck. Nice to see you, sir.

Mr. Chairman, on behalf of the American Dental Hygienists' Association, I want to thank you for the opportunity to testify regarding fiscal year 1999 appropriations for the Department of Health and Human Services and, in particular, the National Institute of Dental Research.

As you know, I am Stan Peck, ADHA's Executive Director. ADHA is headquartered in Chicago. It is the largest national organization representing the professional interests of the approximately 100,000 dental hygienists across the country.

Dental hygienists are preventive oral health professionals who are licensed in each of the 50 States. Dental hygienists are committed to improving the Nation's oral health, a fundamental part of total health. Despite recent advances, oral diseases are still among the Nation's most chronic health problems. The Institute of Medicine estimates that 50 percent of Americans do not receive regular oral health care. Clearly, the Nation's oral health must be further improved, and history shows that research at the National Institute of Dental Research has yielded significant oral health advancements.

Fifty years ago Members of Congress decided to create the National Institute of Dental Research within NIH. This decision has proven to be a wise investment, indeed. NIDR's work in dental research has not only resulted in better oral health for the Nation, it has also helped curb diseases and oral health care costs. Americans save nearly $4 billion annually in dental bills because of advances in dental research and an increased emphasis on preventive health care.

Continued research at NIDR is critical to the future of oral disease prevention and oral health promotion. ADHA strongly endorses NIDR's strategic plan, which calls for expanded research in health promotion, additional public health education efforts, and an increased focus on important oral cancer research.

Since more Americans are lost each year to oral cancer than to cervical cancer or Hodgkin's disease, NIDR research to reduce the morbidity and mortality associated with oral cancer is critical. Dental hygienists, too, play a role in the battle against oral cancer by routinely examining each of their patients for signs of oral cancer. To enable NIDR to continue and to build upon its important research mission, ADHA joins with other dental groups to recommend $240 million for NIDR.

ADHA wishes to take this opportunity to commend this subcommittee and all Members of Congress on passage of the

historic State Children's Health Insurance Program, which was part of the Balanced Budget Act of 1997, and which will extend health insurance to as many uninsured low-income children as possible. ADHA worked hard to promote the inclusion of oral health in the children's health initiative, and ADHA is now working with the States to encourage the strongest possible oral health component in State Children's Health Insurance plans. Inclusion of oral health benefit plans is important because preventable oral disease is the single most common childhood disease.

One approach to improving children's health is to include dental sealants and fluorides in any definition of childhood immunizations. While research to develop a vaccine against tooth decay continues, we can effectively today guard against tooth decay, which is an infectious, transmissible disease, with the combined use of dental sealants and fluorides. Dental sealants and fluorides protect children against tooth decay just as vaccines immunize against certain medical diseases.

ADHA also lends its support to the Division of Oral Health within CDC. Specifically, ADHA urges a budget of $6 million for the Division of Oral Health. This funding level will enable the Division of Oral Health to continue its vital work to control and prevent oral diseases, including its important work in the area of water fluoridation.

ADHA joins the Allied Health Roundtable in supporting Title VII of the Public Health Service Act and recommends full funding for Allied Health Project Grants and Allied Health Advanced Training.

Allied health disciplines constitute fully 60 percent of the health care workforce. With the acknowledged need for cost-effective health care providers, now is the time to augment funding for and recognition of these important allied health programs.

ADHA also urges enactment of comprehensive tobacco settlement legislation, and urges that smoking and spit tobacco prevention programs be funded in that legislation. As preventive oral health specialists, dental hygienists know full well the value of prevention. Cigarette and smokeless tobacco use creates serious and preventable public health problems.

With regard to the Department of Labor, ADHA believes OSHA has an important role to play in promoting employee safety, and ADHA urges the subcommittee to appropriate monies such that OSHA will be able to improve employee safety in the workplace, including the dental hygiene workplace.

In closing, the members of the ADHA appreciate the important contributions of this subcommittee, and those that have been made in improving the quality and availability oforal health services. ADHA is committed to working with you and all Members of Congress to improve the Nation's oral health, a vital part of total health.

Thank you for this opportunity to submit the views of the American Dental Hygienists' Association.

[The prepared statement of Stanley B. Peck follows:]

[Pages 343 - 347--The official Committee record contains additional material here.]

Mr. Porter. Mr. Peck, we appreciate your again coming before the subcommittee to represent the dental hygienists.

Your offices are in Chicago?

Mr. Peck. Yes.

Mr. Porter. Do you live in the Chicago region?

Mr. Peck. Yes, I do, on Wabash.

Mr. Porter. Wabash. You are not a native Chicagoan?

Mr. Peck. No, I am not. You could tell from my accent.

Mr. Porter. Where do you come from?

Mr. Peck. I am a native New Yorker. Lived in Washington for 12 years and lived in Chicago for nearly 5.

Mr. Porter. I would have guessed all that.

Thank you for coming to appear again. We appreciate your testimony. The subcommittee will stand in recess for 3 minutes.

Mr. Peck. Thank you, sir.

[Recess.]

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WITNESS

HARRY TETER, AMERICAN TRAUMA SOCIETY

Mr. Porter. The subcommittee will come to order.

The next witness is Harry Teter, Director of the American Trauma Society, representing the Society.

Mr. Teter.

Mr. Teter. Mr. Chairman, I am very pleased to be here today to represent the Members of the American Trauma Society on several issues that we find extremely important. I am very pleased. I have a statement here that I will put in the record, if I may just make a few comments on the side.

I would, of course, like to be here today and be testifying on behalf of the Institute for Trauma, but we don't have an Institute yet. We have a lot of work that is being done in other areas, and specifically, some that I would like to draw attention to today--the National Center for Injury Prevention and Control at CDC; of course, the good work done at other agencies of HHS; the Emergency Medical Services for Children; and others that are doing good research work in trauma.

There are two things that bring me here today. The Trauma Society is very concerned with proper care for trauma patients, and we are also very concerned that there be good, effective injury prevention programs available.

The statistics on injury are staggering. I am sure they have been presented here before; they are in my testimony as well. But injury is a major cause of health care problems. It is a high-ranking public health care issue and one that we all must be concerned with. In the trauma business we see it all too frequently, every day. We see injuries that could have been avoided, could have been prevented, and we hope that in the future that will happen with good programs and good education. There is no denying the fact that we must have good care. To that end, I want to applaud the research that is being done and

encourage more research to be done in the area of trauma care, acute care.

There is one area in particular that I hope we can address in the future. That is measuring the true value of trauma systems. We know they save money; we know they save lives. But daily, that is questioned, as we look at--because they are very highly--they use a lot of resources, and managed care, et cetera, wants to say, well, did they really need all this care? Did they really need all these resources?

We know they do. They are saying, well, prove it. We would like to set out to do that, but we would like to have an objective person or organization really examine the outcomes of trauma in the trauma center and the trauma system versus a nontrauma system.

These systems, as I say, we know save lives. We must continue to build them across the country.

Actually, we would like to see that nobody even gets into the trauma system at all. Therefore, I want to applaud the work being done by the National Center for Injury Prevention and Control at CDC. I think in the short time they have been in existence they have a remarkable story to tell of excellent research they are doing.

One thinks immediately of the good work being done on helmet use, on smoke alerts, smoke detectors, et cetera. But there is far more that is being done there. I hope that I will be able to, in the next month, present a real overview to you of all of the research that the various centers are doing.

The CDC group there funds research, as you know, both at the Center, and they fund programs of research in 10 injury control centers across the country. The stories, as I say, are quite interesting, because we really look at all types of injuries, both in the young and the old; and, too, I don't know if we can consider ourselves in between, but I would like to think so. But at any rate, they are looking at these injuries very carefully, and how they can be prevented.

But most importantly, too, is once we know the prevention and what works, we have to get the word out there. That is another function that the Centers for Disease Control's Injury Prevention Program is doing, and needs to continue to do.

So today, I would strongly urge the committee to giveincreased funding to the Center for research and for the education programs that they are doing, and the work they are doing in what they call Safe America. It is a truly worthy cause.

I would like to also say that the work that is being done at the Emergency Medical Services for Children is extremely valuable for childhood injuries, and we applaud that work and also hope that that will receive increased funding.

One program that I think should be looked at, and that is the Emergency Medical Services--well, the block grant, Preventive Health and Health Care Block Grant at CDC. Years ago we had a specific categorical program on Emergency Medical Services. It was a superb program that unfortunately got put into a block grant. It is being given short attention these days, and I hope that we can eventually see that program moved out, possibly going into the Center for Injury Prevention.

At any rate, thank you for your time here today, and I will be glad to answer any questions.

[The prepared statement of Harry Teter follows:]

[Pages 350 - 359--The official Committee record contains additional material here.]

Mr. Porter. Mr. Teter, how much trauma is accidental, as opposed to intentional?

Mr. Teter. Mr. Chairman, I truly cannot answer that question, because I would take a guess that it is probably about 60/40, 60 unintentional, 40 intentional. The highway trauma that comes from car crashes I would lump as unintentional. One might say that drunk driving, et cetera, is not unintentional. But if we do the car crashes, which are roughly about 50 percent of the trauma we see, we certainly see trauma in the workplace. We see trauma at home that is unintentional, and injuries. It may be even 70/30.

Mr. Porter. Thank you very much for your testimony this afternoon. We appreciate it.

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WITNESS

BRUCE M. CARLSON, Ph.D., M.D., AMERICAN ASSOCIATION OF ANATOMISTS

Mr. Porter. Bruce M. Carlson, Ph.D., M.D., President, American Association of Anatomists, Professor and Chairman, Department of Anatomy and Cell Biology at the University of Michigan Medical Center, Ann Arbor, Michigan, testifying on behalf of the American Association of Anatomists.

Dr. Carlson. Thank you very much for the opportunity to testify. As you mentioned, I am testifying as President of the American Association of Anatomists. This association is a professional organization consisting of somewhat over 2,500 members who conduct research on the structure and function of the human body. Our members are conducting the research in virtually all major universities, medical schools, and government laboratories. In addition, anatomists teach a good share of the first-year medical curriculum.

Thanks to the continuing support of the Congress, at least in my opinion, the American biomedical research establishment probably has no equal anywhere else in the world. I have had the personal privilege of being able to continue extensive research in a number of countries, including the Soviet Union, Czechoslovakia, Finland and The Netherlands. In the former Eastern Bloc, research is typically conducted from the top down in terms of planning, and research was conducted in institutes separated from the universities. In my experience, in all of the countries I have been in, I have encountered very good research, but in no country has the environment for basic research been as conducive to progress as that we have in our country.

The investigator-initiated research in our own universities is very important because of the stimulus we get from students and trainees who really provide energy to the research process;

and also from the intellectual drive that stems from investigators who are working on projects in which they have an intense personal interest. I strongly believe that the unique entrepreneurial spirit of basic biomedical research in this country is the engine that drives much of our productivity.

The American Association of Anatomists supports the recommendations of the consensus conference of FASEB for the fiscal year 1999 budget of the NIH, and specific points are in my written testimony. I will not reiterate them here.

At present, biomedical science, as you well know, is progressing at an absolutely unprecedented rate. As a writer of embryology textbooks, I am continually amazed and frankly overwhelmed by the amount of new information that has come out in the last 8 or 10 years. About 4 years ago now, I had published a new text in medical embryology. Within 6 weeks of publication significant parts of the book were completely out of date because of major new research findings.

Just last week, a colleague of mine at the University of Michigan was lecturing to the freshman medical students ondevelopment of the brain and spinal cord. Fully three-quarters of her lecture consisted of information that we did not know 4 years ago.

My own current laboratory research has moved from studies of embryonic development to studies of aging and, in particular, the aging of muscle. I am trying to understand the basis for reduced muscle function and the poor regenerative capacity of muscle as an individual ages. This research has been supported by the National Institute on Aging.

Other research that is being supported by this same NIH Institute involves the application of guided exercise programs to individuals in their nineties who have very poor mobility. Thanks to some scientific studies that have been conducted on human exercise, individuals who literally had to have assistance to get out of bed or go to the bathroom could now fulfill these functions in an unassisted manner; individuals who could not walk fast enough to get across the street during the course of a normal green light can now walk across the street unassisted.

Despite the generous support of biomedical research, there is still much excellent work that remains to be done. Other projects have suffered lapses in terms of the continuity of funding. Let me stress the importance, number one, of peer review and, number two, the continuity of funding issue. Peer review is very important in our scientific process, not only for deciding who will or will not get research grants, but for maintaining a level of science. We often find that individuals who have excellent research projects, but who have had difficulty with one aspect because of peer review may suffer a 6- to 9-month period where funding is not available. If this shuts down the laboratory, it may be 2 or 3 years before that laboratory is up to full function. Therefore, I think it would be very important to have mechanisms in place for bridge funding for the basic functions of a laboratory that is in this particular interim period.

The maintenance and upgrading of research infrastructure is also very important. To me, infrastructure goes far beyond bricks and mortar, but it refers to scientific capabilities. Examples would be common courses for specialized equipment that

would be beyond the reach of an individual laboratory or national center for the care and maintenance of rare breeds of research animals.

Contemporary biomedical science is evolving at an unprecedented rate. To maintain this momentum, we must continue to bring new brains and energy representing all elements of our population into the national research effort. The American Association of Anatomists appreciates and strongly supports programs for the NIH for training of diverse groups for independent research careers.

Mr. Chairman, we in the biomedical research community recognize and thank you for the generous support that the subcommittee has shown us over the 104th Congress and 105th Congress. The American public and Congress have placed a great responsibility on the biomedical research community to translate this support into improved national health and well-being. We accept this challenge and I hope that the products of our efforts will speak for themselves as advances in science are incorporated into medical products and practices.

Thank you very much.

[The prepared statement of Bruce Carlson, M.D., follows:]

[Pages 363 - 370--The official Committee record contains additional material here.]

Mr. Porter. Dr. Carlson, thank you for your good testimony.

I am pleased to see that a professor of my alma mater is president of the association, and we were happy to have you here today and hear what you have to tell us. We have made some important notes that we will follow through on and appreciate your coming to testify.

Dr. Carlson. Thank you very much. I appreciate that.

Wednesday, January 28, 1998.

WITNESS

JOSEPH WEISENBURGER, INTERSTATE CONFERENCE OF EMPLOYMENT SECURITY AGENCIES

Mr. Porter. Joseph Weisenburger, Deputy Commissioner, New Hampshire Department of Employment Security and Interstate Conference of Employment Security Agencies, in behalf of the Conference.

Mr. Weisenburger.

Mr. Weisenburger. Thank you. Mr. Chairman. I am here today to testify on behalf of the Interstate Conference of Employment Security Agencies, a national organization of public officials who administer the Nation's unemployment insurance programs, the public employment service, the labor market information programs, and in 41 States, the job training programs, and now a growing number of welfare-to-work programs.

As you know, the employment security system is funded by a dedicated tax paid by employers. While this tax is sufficient to maintain and fund the proper and efficient administration of

our programs, because of the focus on the Federal deficit and the inclusion of these trust funds in the calculations of the budget, we have received substantial cuts in our programs which have jeopardized the integrity and effectiveness of those programs. We ask you to begin the process of restoring the appropriations to our very important programs.

For the public Employment Service, we first ask that you increase the appropriation from its current level of $761 million to $811 million. The justification for that is that several years ago, this Congress began funding the creation and implementation of one-stop career centers. It has now become obvious to the Department of Labor and to the States that the public Employment Service will be the glue that holds these one-stop systems together.

So we urge you, in order to keep the successes that we have already achieved in this one-stop system moving forward, we urge you to fund the Employment Service at this new higher $50 million level as a beginning to--as these one-stop systems start to come together.

For the unemployment insurance program, first we would like to thank you for the special $200 million appropriation you granted to the States so we could deal with the problems of the millennium. While it is a very close time frame, without that funding we certainly would have had serious disruptions in the payment of unemployment benefits.

The unemployment insurance program for the past 62 years, the partnership between the Federal Government and the States, has worked fairly well. The Federal Government, the Department of Labor, that is, funded the States using a formula that took into consideration the workload in each State and the cost of doing business in each State. However, because of the focus on the budget problems, we no longer fund the system in that manner.

As an example, this year the Department of Labor, in trying to determine what the base allocation would be for the States, estimated that the States would need sufficient resources to process 2 million claims a week. The final appropriation only turned out to fund 1.8 million claims a week. That means that currently every week the State employment security agencies are processing 200,000 claims without any Federal general revenue--I am sorry, without any of the dedicated overage amount in taxes.

We urge you to reconnect the funding of the unemployment insurance system to that workload formula that actually funds the States based upon their actual costs, and provides the services that unemployed workers who lose their jobs through no fault of their own need.

There are several other miscellaneous programs that we run. We ask you, and it is particularly an urgent request for the Alien Labor Certification program--2 years ago the Congress cut the appropriation for this program by 50 percent. That cut, tied with significant workload increases, has caused enormous backlogs at the State level. Employers are furious. It has caused a black eye on the public Employment Service. One State received a bomb threat, others have received other threats of violence. Some States, because of the seriousness of this, are considering discontinuing the administration of this program

unless the funds are restored to what we believe is the appropriate level of $50,500,000.

For the Workforce Opportunity Tax Credit, we ask you to continue the funding level at $20 million that we currently have this year.

For our Labor Market Information programs we ask a small increase in that very important program, which is the economic cornerstone to economic development at the State level; and for the information that is necessary at the one-stop career centers, we ask $55 million this year for the cooperative program with the Bureau of Labor Statistics.

Finally, for our veterans' programs, which are seriously underfunded, we ask that the Congress begin a process of funding our disabled veteran representatives and our local veteran representatives to a level that guarantees at least one veterans' representative in each of the one-stop career centers throughout this country.

Thank you, Mr. Chairman. I would be glad to answer questions.

[The prepared statement of Joseph Weisenburger follows:]

[Pages 373 - 379--The official Committee record contains additional material here.]

Mr. Porter. Mr. Weisenburger, on the State operations for the unemployment compensation trust funds, staff tells me we level-funded that between fiscal 1997 and 1998.

I thought I had heard you say that you were only able to do 1.8 million out of 2 million operations. Was it underfunded to start with? Because it seems to me in this economy, our unemployment is at an all-time low. I think the President said last night it was at a 27-year low.

Mr. Weisenburger. The unemployment rate is low. There is a different between the total unemployment rate and the unemployment insurance program.

Mr. Porter. I understand, but it should be also tracking pretty comparably, shouldn't it?

Mr. Weisenburger. Yes, it is. It is low. Next year actually, we project taking 9.1 million claimants, and that is still a lot of people, even though the unemployment rate is low. But we have been funded based upon our workload. If the workload goes down, our funding goes down and that works, and we respect that process; but the funding has been cut way below those levels that are needed to process even low claims.

Mr. Porter. I see. So it was low to begin with?

Mr. Weisenburger. Two million low. Actually, we probably take 2.7 million claims every week.

Mr. Porter. The amount of money that was allocated forfiscal year 1997, you are saying, was inadequate to start with?

Mr. Weisenburger. That's correct, based upon the cost of doing business at the State level, they only processed 1.8.

Mr. Porter. Thank you very much for your testimony.

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Wednesday, January 28, 1998.

WITNESS

JOHN SUTTIE, AMERICAN SOCIETY FOR NUTRITIONAL SCIENCES

Mr. Porter. John Suttie, Ph.D., professor of biochemistry and nutritional sciences, testifying on behalf of the American Society for Nutritional Sciences.

Dr. Suttie, it is good to see you.

Mr. Suttie. It is good to see you.

I am John Suttie, professor of the Department of Biochemistry and Nutritional Sciences at the University of Wisconsin. I have also served as president of the Nutrition Society and recently served as president of the American Society for Experimental Biology.

It is as a representative of the Nutrition Society that I appear before you today in support of the research budget of the National Institutes of Health. Our society is the principal professional organization of nutritional research scientists in the United States. It represents 3,500 members whose purpose is to develop and extend the knowledge and application of nutrition.

Our leaders participated in FASEB's Federal Funding Consensus Conference last month, and we endorsed their recommendation of a 15 percent increase for the fiscal year 1998 NIH budget. This increase would represent an initial step toward the goal of doubling the NIH budget over the next 5 years, a goal which many of your colleagues in the House and Senate have publicly supported. We are also pleased at the recent indications of increased NIH support from the administration.

All citizens should be grateful to this subcommittee for the continued support of the NIH budget during the period of strong competition for limited resources. As the cornerstone of preventive medicine, nutrition is the key to enhancing individual and public health.

Nutritional research, although multidisciplinary, has one goal: To understand the role of appropriate nutrition in growth, development, quality of life, decreasing disease risk, and treatment of existing disease. Inappropriate nutrition is a primary factor in unattained genetic development, reduced productivity, and increased susceptibility to diseases such as heart disease, cancer, stroke, liver disease, and atherosclerosis. Diseases like these cost our Nation billions of dollars annually in health care and lost productivity.

According to a 1997 report from NIH, the annual cost of illness related to cancer, diabetes, heart disease, and Alzheimer's disease is nearly $450 billion, approximately $203 billion in medical care and $245 billion in lost wages and productivity.

It is important to recognize that optimal nutrition is one of the best means of keeping these health care costs down. Our society advocates that the level of NIH support for nutrition research reflect the important role of diet in health promotion and in the prevention and treatment of disease. Let me share with you a few examples of progress that has been made.

First, it has been found that caloric restriction in diets

extends the life-span and health span of primates. Rhesus monkeys subjected to dietary restriction were shown to have less body fat, increased insulin sensitivity, lower fasting glucose levels, improved glucose tolerance, reduced oxygen consumption, and lower weights. Understanding of these nutrient-related biologic responses that bring about these alternatives and alterations will require increased funding for this area of research.

Second, ongoing studies in transgenic gene ``knockout'' mice show that caloric restriction used as a dietary perturbation has delayed tumor appearance and development and prolonged survival significantly. This finding establishes that dietary manipulation is an effective way to reduce cancer incidence.

Third, research has found that fish, other seafoods, and fish oil contain a class of polyunsaturated fatty acids that may reduce the risk of coronary heart disease. Evidence shows that death due to heart disease is lower among men who consume higher amounts of these fatty acids.

The nutrition community is proud of our past, and our ongoing achievements show great promise. A renewed andlong-term national commitment to invest in biomedical research for the continuing benefits of society is essential, and nutrition research will play an important role in this development.

I mention three research areas for funds directed towards nutritional research which will be particularly cost-effective: Aging, cancer, and cardiovascular disease.

Another opportunity is prepared by the success of NIH and other agencies to sequence the human genome. This will not only allow physicians to effectively target drug therapy to individuals but will also open the door to the identification of nutrient requirements of each individual. This area will also require increased funding.

Finally, it is important that we adequately train young scientists who will be able to prepare us for new challenges. Ensuring that the new generation of nutritional scientists will establish the links between nutrients and gene expression are trained to use the latest knowledge and tools developed by molecular and cellular biologists is essential. These training activities will require funding.

Members of the American Society for Nutritional Science are aware that allocation of resources requires you to make difficult choices. We urge you to continue the support you have provided the NIH in recent years, and we pledge our support in efforts to influence the budget allocation process.

Thank you again for the opportunity to testify.

[The prepared statement of John W. Suttie follows:]

[Pages 383 - 394--The official Committee record contains additional material here.]

Mr. Porter. I was delighted particularly with your last sentence.

Dr. Suttie. I think we all recognize that this is essential.

Mr. Porter. Yes, it is essential, and it will make all the difference in the outcome, so we will do our best. I said this morning, I am not sure I said it this afternoon, but let me say it anyway so we are clear--let me ask you, were you encouraged by what the President had to say last night in the last few sentences of his State of the Union about research?

Dr. Suttie. I was encouraged, certainly, that I think we have seen a stronger position from the President than we have seen in recent years. I think that those of us that are actively involved in biomedical research would perhaps like to see a somewhat larger allocation than he is talking about, but I think we see this as a base and a floor to start from. But I think it is encouraging to see us start with a higher level of support.

Mr. Porter. I said basically the same thing, Dr. Suttie, that I was encouraged that normally, given the priority at which the subcommittee places biomedical research, that it puts a floor under it, except that a good portion of the increase in spending in the discretionary accounts under his budget will be required to be supported by the revenue increases that he also proposes, including the tobacco settlement.

While I think increased funding from tobacco taxes or related revenues from the tobacco industry are wonderfully justified, I also know that a lot of Members of Congress don't like to increase any kind of revenue sources, and it is problematical that we will get the revenues to support the spending. That will make it much more difficult.

You agree with that, I assume?

Dr. Suttie. The money from the tobacco settlement is not there yet, and there is a question how much will be there.

Mr. Porter. There is a question as to whether this will actually be able to be addressed in this fiscal year because of electoral politics, among other reasons, and also because it is such a huge, difficult, complex subject to resolve. So I think we have to worry about that.

We thank you, Dr. Suttie, for testifying again.

Wednesday, January 28, 1998.

WITNESS

K. KIMBERLY KENNEY, THE CHRONIC FATIGUE AND IMMUNE DYSFUNCTION SYNDROME ASSOCIATION

Mr. Porter. K. Kimberly Kenney, executive director, the Chronic Fatigue and Immune Dysfunction Syndrome.

Ms. Kenney.

Ms. Kenney. Good afternoon, Mr. Porter. Thank you for the opportunity to appear before the subcommittee today.

My name is Kimberly Kenney. I am executive director of the CFIDS Association of America.

Mr. Porter. I am sorry we don't have the word ``Association'' in here. I assumed it was missing for some reason, but it was just left out. I apologize.

Ms. Kenney. Our association is the world's largest and most active charitable organization dedicated to conquering chronic

fatigue and immune dysfunction syndrome, CFIDS.

As you know, Mr. Chairman, CFIDS is a serious and complex disease characterized by incapacitating fatigue, persistent flu-like symptoms, intractable pain, and Alzheimer-like cognitive deficits. The cause has not yet been identified, and there is no cure or effective treatment.

CDC estimates that half a million American adults and children suffer from strictly defined CFIDS. This committee, with your personal support, Chairman Porter, has provided leadership and vision through the Federal agencies which must meet the needs of persons with CFIDS.

As I have been honored to do for each of the last 3 years, I come before you today to report that progress isbeing made in the understanding of CFIDS, but I also point out certain critical areas where there are problems.

Many important signs of progress are outlined in my written testimony, and I wish to highlight just one, what I consider to be the most significant event of 1997, a public-private partnership to educate health care workers about CFIDS.

This medical education program was produced by the Office of the Assistant Secretary for Health with collaboration from many Federal agencies and patient representatives. It was conceptualized and written by a team of patient advocates and staff from HHS, NIH, CDC, broadcast across the country by satellite by CDC, and has been continuously rebroadcast over the Internet. It is also available on videotape to health care providers.

The CFIDS Association's partnership with HRSA's area health education centers resulted in 78 new satellite viewing sites where over 1,200 provider participants learned about the diagnosis and management of CFIDS. Federal officials, health care professionals, and advocates have recognized this program as an important first step in a broad-based medical education initiative.

As a result of the satellite program and other Federal and private sector activities, public consciousness was raised this year and the legitimacy of CFIDS better established. But we are at a critical juncture. Unfortunately, Mr. Chairman, there are several areas in which the Federal effort has stalled. I should like to bring these to your attention now and request that you address these issues at the appropriate times during this year's appropriation hearings.

First, in regards to the CDC's work on CFIDS, our intensified efforts over the past several months to track the use of Federal funds allocated to CFIDS research at CDC have been met with unclear answers that do not withstand close scrutiny. With support from the Office of the Assistant Secretary for Health, we have assurances that CDC will provide a complete accounting of CFIDS-related funds for fiscal year 1996 and 1997 by February 28. Should CDC still fall short of providing full accountability for claimed expenditures, we ask that you raise this issue with CDC officials during their appearances before this committee this spring.

The CFIDS program at NIH appears to have experienced a slight decrease between 1997 and 1998. Particularly in light of the 7 percent increase in NIH funding overall during that period, CFIDS funding is moving in the wrong direction. We have

tried to verify this decrease, but the final funding numbers for fiscal year 1997, which were to be ready October 22 and then November 15, have still not been made available to us.

A downward trend underscores the need for clearer direction from Congress. Over the past 5 years, the association and Congress have encouraged NIH to focus efforts and expand research. The focus has yielded scientifically sound investigations to pursue, yet the expanded funding has not been forthcoming.

We understand the subcommittee's reluctance to earmark, but in light of this discrepancy between an increase in overall NIH funding and the erosion of CFIDS funding, we have no choice but to ask once again that you direct NIH to provide an additional $10 million for extramural grants.

Persons with CFIDS continue to experience serious obstruction when seeking disability benefits from the Social Security Administration. These obstructions stem from lack of understanding by the Social Security Administration of the debilitating nature of CFIDS.

While we were initially encouraged by meetings with SSA's Office of Disability, their interest has not been sustained. We ask the committee to direct the commissioner to appoint a task force to ensure both attention and follow-up to the task of educating SSA personnel at every level about CFIDS.

Detailed requests on CDC, NIH, as I say, and HRSA are provided in my written testimony. Mr. Chairman, you are familiar with our issue, and I believe you will recognize some of these requests from past years. The association has strived to make consistent, reasonable requests, with the goal of providing greater clarification of issues critical to those who suffer from the disease. Using this strategy, we have been rewarded by the committee in many areas. However, as you can see, there are still great challenges ahead and your support is essential to overcoming them.

Thank you for your efforts on behalf of people with CFIDS, for your time and attention this afternoon, and for your thoughtful consideration of our request.

[The prepared statement of Kimberly Kenney follows:]

[Pages 398 - 406--The official Committee record contains additional material here.]

Mr. Porter. Ms. Kenney, I get the message. There was a witness in this morning's session that testified in his own behalf and raised the question of the words that describe the disease. It started as Epstein-Barr virus, or chronic Epstein-Barr syndrome, and has now been called CFIDS, and he is saying that we ought to change that. Do you agree? I thought he said that the association was working with him on this.

Ms. Kenney. There is very broad-based support to change the name. I believe that the differences come in at what point it is appropriate to do so. I think most of the scientific community would prefer to wait until there is a scientific advance that would justify a change to another medically-based name. The patient community believes that they are stigmatized

enough and would prefer that a name change occur sooner rather than later. We are trying to move the process along so that we can build consensus between both the patient and the medical communities.

Mr. Porter. Am I correct that Epstein-Barr and CFIDS are one and the same, or am I not correct?

Ms. Kenney. Epstein-Barr was originally thought back in the mid-eighties to be a potential cause of the syndrome. That was ruled out, I think, in 1988.

Mr. Porter. So there is no connection?

Ms. Kenney. Most doctors will tell their patients that you have high Epstein-Barr titers and therefore you must have chronic fatigue syndrome, which there is no relationship between the two.

Mr. Porter. We thank you very much for your testimony again. It is nice to see you. I did get the message.

Ms. Kenney. Thank you.

Wednesday, January 28, 1998.

WITNESS

THOMAS A. GENNARELLI, M.D., THE COALITION FOR AMERICAN TRAUMA CARE

Mr. Porter. Thomas A. Gennarelli, M.D., professor and chair, Department of Neurosurgery, Center for Neuroscience, Pennsylvania head injury center, Medical College of Pennsylvania, Hahnemann School of Medicine, Allegheny University of the Health Sciences, testifying on behalf of the Coalition for American Trauma Care.

Dr. Gennarelli.

Dr. Gennarelli. Mr. Chairman, I am very pleased and very proud to have the opportunity to provide testimony today on the importance of supporting injury prevention trauma and burn care activities across the U.S. Public Health Service.

Although I am professor and chair of the Department of Neurology at Allegheny University, of the Health Sciences, I am here today as a member of the board of trustees of the Coalition for American Trauma Care.

Injury or trauma is one of the most, if not the most, important public health problems facing the United States today. It is the leading cause of death for Americans from age 1 through age 44, and more than 145,000 people die each year from injury, 88,000 from unintentional injuries, such as car crashes, fires, and falls, and 56,000 from violence-related causes. This relates to 400 deaths per day or 1 death every 3.6 minutes.

Of perhaps greater importance, injury is the most frequent cause of disability and loss of productivity. Millions of Americans survive injury each year, but many are left temporarily disabled, and some permanently disabled, with severe head, spinal cord, and extremity injuries. Because injuries strike the young disproportionately, injury is also the leading cause of years of lost work productivity, and at an estimated cost of $224 billion each year, trauma is our Nation's most costly disease.

This is background. The Coalition would like to provide the subcommittee with funding recommendations for injury prevention and treatment in four Federal public health agencies--the NIH, CDC, HRSA, and AHCPR.

Regarding NIH, the Coalition supports the Ad Hoc Group for Medical Research Funding's recommendation of a 15 percent increase in funding for the NIH for fiscal year 1999. However, the Coalition is concerned that as much of this increase as possible come from funds that are in addition to currently tightly capped discretionary accounts, so that other public health programs will not suffer.

The Coalition also feels that some portion of this increased funding should be earmarked to enhance more trauma and burn care-related research. The Ad Hoc Group has called on the leadership of the NIH, with its extramural partners, to establish a process of consultation and planning to develop a comprehensive, creditable approach to allocating new resources based upon the most promising scientific opportunities and the most pressing public health needs.

Given national injury statistics, it is hard to argue with the reality that injury ranks as one of the most pressing public health needs in the United States today. Yet despite its huge impact on American society, less than 1 percent of the total NIH funding supports any research on trauma, basic or clinical.

The Coalition, as did a recent NIH trauma research task force, recommends increased funding for several resources within the NIH, including NIGMS, NIAMSD, NIAMSD, NINDS, NICHD, the National Center for Medical Rehabilitation, and the National Institute on Aging.

The Coalition also supports an additional $20 million for CDC's National Center for Injury Prevention and Control to further its new initiative, Safe America, through injury control. This is the amount the Center needs to begin major implementation of proven injury prevention strategies, such as bicycle helmet use, trauma care systems, and residential smoke detectors.

The Coalition also urges you to provide $8 million in fiscal year 1999 to fully fund the Traumatic Brain Injury Act. Traumatic brain injury is the leading cause of trauma-related death and disability and is the silent epidemic that compounds itself every year, but about which very little is still known, despite some of us spending morethan a quarter of a century in this research area.

The Coalition has other recommendations that are contained in my written statement.

The Coalition for American Trauma Care appreciates the support this subcommittee has provided to many trauma, injury prevention, and burn-related programs in the past. However, much remains to be done to address this leading public health problem so that we can achieve substantial health and social welfare cost savings through increased research regarding the timely treatment, rehabilitation, interventions, and prevention of trauma.

The Coalition looks forward to working with you to achieve these goals and thanks you for the privilege of this august floor.

[The prepared statement of Thomas A. Gennarelli, M.D., follows:]

[Pages 410 - 417--The official Committee record contains additional material here.]

Mr. Porter. Perfect timing.

Dr. Gennarelli, what is the relationship between the Coalition for American Trauma Care and the American Trauma Society?

Dr. Gennarelli. The Coalition for American Trauma Care is comprised of numerous scientific organizations and is the voice for that group. The American Trauma Society has a different constitution.

Mr. Porter. Is yours scientific and theirs patients, basically?

Dr. Gennarelli. Essentially so, yes.

Mr. Porter. I asked Mr. Teter, who represented them--and I am not sure you were in the room then--to break down between intentional and accidental trauma. What percentage falls in each group, do you know?

Dr. Gennarelli. It depends on how you want to present it. If you want to take all patients who experience injury, you probably would say 80 nonintentional, 20 intentional. If you include those just who die, because gunshot wounds have a much higher mortality than other kinds of injuries, then the proportion gets to be more 60/40. The deaths last year were 88,000 unintentional, 56,000 intentional.

Mr. Porter. I see. Thank you very much for your testimony. We will do our best.

Wednesday, January 28, 1998.

WITNESS

JOANNE PEASE, IMMUNE DEFICIENCY FOUNDATION, INC.

Mr. Porter. Joanne Pease, Member, Immune Deficiency Foundation, Incorporated, testifying on behalf of the Foundation.

Ms. Pease. Thank you for the opportunity to speak here today on behalf of the Immune Deficiency Foundation.

My three sons and my nephew have primary immunodeficiency diseases, which means that they were born with incomplete immune systems. My name is Joanne Bakken Pease, and I am a volunteer with the Washington State chapter of the Immune Deficiency Foundation.

As I tell my story today, I am mindful of the significant work being done by the Immune Deficiency Foundation on behalf of the approximately 40,000 individuals affected by these genetic disorders of the immune system. The IDF is developing a national registry of U.S. patients suffering from the most common of these disorders funded by a grant from NIAID. The registry is providing an important resource to physicians and investigators by giving them access to a more clinical

understanding of these diseases.

The clinical information contained in these registries will help determine the frequency of complications, long-term prognosis, and possibly open the gateway for gene therapy. As a mother of three affected children, I am proud of the work of the Foundation, and, in sharing my story, I hope to express to you the need for this work to continue.

In November of 1985, my eldest son, Curtis, received his vaccine for measles, mumps, and rubella. Curtis got the mumps from this vaccine in February of 1986, and the doctor told me, these things happen. After 3 years of constant colds and pneumonia, Curtis was diagnosed with X-linked Agammaglobulinanemia. I was thankful when I learned there was a treatment for him. However, the treatment consisted of a very painful injection administered every 10 days. This treatment, a pooled plasma derivative, replaced portions of his incomplete immune system. However, the pain involved caused this therapy to be a source of terror in our household.

When my second son, Jeff, was 10 months old, we learned he had contracted polio from the oral vaccine, signalling the presence of the same immunodeficiency. He was left with a withered right leg and a terribly deformed foot. Now both my beautiful boys receive these painful shots.

Three years later, they both started getting their medicine intravenously. Intravenous immune globulin was less painful and more effective, and it reduced our infusions to once a month. Jeff has had 6 very painful orthopedic surgeries, including tendon transfers and releases, hip rotation, hip reconstruction, leg rotation, and ankle repositioning. He is now ready for his seventh and eighth operations, which will be complicated leg lengthening.

My nephew, Joshua, was born in 1988 and my third son, Mitchell, in 1990. Both were diagnosed with XLA at birth and began their treatments.

We have learned to cope with the care necessary to keep our children alive. However, issues related to the safety of the blood supply make me feel that my children are so vulnerable. Between the four boys, they receive 70 infusions per year.

My children's lives are not what I envisioned for them. The pain that I feel for the loss of my dream will never go away. We need to continue the focus on medical research so perhaps future generations will have the option of gene therapy and not have to suffer years of chronic care.

For fiscal year 1999, the Immune Deficiency Foundation recommends the National Institute of Allergy and Infectious Diseases receive a 15 percent increase over last year. This percentage translates into $202.7 million over fiscal year 1998 and would bring NIAID's total appropriation to $1.55 billion.

In addition, Mr. Chairman, I would like to make clear that although IDF strongly supports the concept of doubling NIH's overall budget in the next 5 years, we do not believe that these increases should come at the expense of other important Public Health Service programs.

As you regard your decision to increase funding, please remember my boys and the approximately 40,000 primary immunodeficient patients affected by your vote.

[The prepared statement of Joanne Bakken Pease follows:]

[Pages 420 - 425--The official Committee record contains additional material here.]

Mr. Porter. Ms. Pease, I will remember your boys. My father had polio and had those same operations on his leg, or at least some of them that your son has had to undergo.

Is this covered by insurance? How do you cope with the costs, in addition to the emotional problems?

Ms. Pease. Our two boys have to be on a separate policy from my husband's group plan, because their costs are so high. The company does pay the premiums, and it is good insurance. For their infusions, we have had to go out of contract.

Mr. Porter. Did you have any indication that there was anything wrong until they contracted these diseases?

Ms. Pease. None; no family history. But, obviously, my sister and I are both carriers of this X-linked disease.

Mr. Porter. Let me ask you, do you think NIAID is putting this at a high priority?

Ms. Pease. I am not aware of the prioritizing. That is not my realm.

Mr. Porter. Now that I think about it, that is an unfair question for you.

Ms. Pease. I am hoping that it is up there.

Mr. Porter. Thank you very much for your testimony.

Wednesday, January 28, 1998.

WITNESS

MARIANNE PUCKETT, MEDICAL LIBRARY ASSOCIATION/ASSOCIATION OF ACADEMIC HEALTH SCIENCES LIBRARIES JOINT LEGISLATIVE TASK FORCE

Mr. Porter. Marianne Puckett, chairperson, Medical Library Association/Association of Academic Health Sciences Libraries Joint Legislative Task Force.

Ms. Puckett.

Ms. Puckett. Mr. Chairman and members of the subcommittee, I am Marianne Puckett, associate professor of medical library science at the Louisiana State University Medical Center in Shreveport, Louisiana. I appreciate the opportunity to testify today on behalf of the Medical Library Association and the Association of Academic Health Sciences Libraries regarding the fiscal year 1999 budget of the National Library of Medicine.

First, let me thank you and the members of this subcommittee for your leadership in securing a 7.2 percent increase for the National Library of Medicine in fiscal year 1998. Regarding the NLM 1999 fiscal year budget, I will address three issues: First, basic services and personnel; second, outreach; and third, access to health care information.

As we approach the next century, the medical library community believes that basic library services must still be the foundation for NLM's long-term success as a service agency. Unfortunately, the level of demand for basic NLM services and the rate of increase in the cost of medical journals and books

have both been in the 10 to 15 percentrange in recent years, far outstripping the library's budget increases.

Moreover, NLM's level of staffing has remained the same over the past few years. Maintaining the current standard of acquisitions, indexing, cataloging, database searching, and lending will become more and more difficult, if not impossible, unless NLM's budget and level of staffing are increased to reflect these rising work loads and costs. As a result, we urge the subcommittee to consider the need for increasing support in both budget and staff positions so NLM can meet its increasing service needs and ensure the quality of its programs is not compromised.

Second, NLM's outreach programs are of particular interest to MLA and AAHSL. These activities, designed to educate medical librarians and other health care professionals about NLM and the information services it provides, have proven to be extremely successful in improving the quality of our Nation's health care.

Although NLM has educated a significant number of health care professionals through its outreach initiatives in the 1990's, more work needs to be done in this area. There are still far too many health care workers in all parts of the country who are unaware that NLM and the National Network of Libraries of Medicine even exist. The need for a vigorous outreach program is now more important than ever.

In 1997, NLM's database became available free over the Internet and Worldwide Web, opening them up to the general public and health professionals alike. NLM's outreach mission will not be complete until all who need access to science-based health knowledge are familiar with NLM and the information resources it provides.

Third, Mr. Chairman, the National Library of Medicine continues to be the critical investment agency for increasing the public's access to health care information. This is especially true for people living in medically underserved areas. For example, my institution maintains several telemedicine and distance learning sites throughout rural Louisiana. With the support of NLM technology and NLM's invaluable programs, we provide access to health information and educational resources to some of our State's most at-risk citizens.

In addition to support of telemedicine, NLM's High-Performance Computing and Communications Initiative and free Internet Medline have empowered Americans with the ability to access the world's most expensive library of medical data directly from their own personal computers.

The health sciences library community applauds Congress for its foresight in providing NLM with the necessary resources to develop these programs. There is no question that these technologies are having a profound influence on the delivery of health care across the country. To realize the full potential of these programs, though, it is crucial that Congress continue to provide NLM with adequate funding in fiscal year 1999.

Mr. Chairman, with the endless advances of the Information Age, it is obvious that the National Library of Medicine will play a major role in delivering health care in the 21st century. Therefore, the Medical Library Association and the

Association of Academic Health Sciences Libraries recommend a 15 percent increase in funding for the National Library of Medicine in fiscal year 1999. This figure represents a $24 million increase over fiscal year 1998 and would bring the Library's total fiscal year 1999 appropriation to $185.4 million.

In closing, I would like to make clear that although the medical library community strongly supports the concept of doubling NIH's overall budget in the next 5 years, we do not believe that these increases should come at the expense of other important Public Health Service programs.

Once again, Mr. Chairman, thank you very much for the opportunity to testify this afternoon. I would be pleased to answer any questions you may have.

[The prepared statement of Marianne Puckett follows:]

[Pages 429 - 435--The official Committee record contains additional material here.]

Mr. Porter. Mrs. Puckett, thank you for your testimony.

It seems that a number of our witnesses have put that disclaimer on at the end. I certainly understand it. I also don't want to get people's hopes up more than is justified by the fiscal situation in which we find ourselves. The first priority of the Congress will be to balance the budget, so that unless there are substantial increases in revenues of the type the President has proposed in his State of the Union Address, and will propose in his budget, I think it is going to be very difficult to reach the figure that all the witnesses have uniformly mentioned of 15 percent.

That doesn't mean we are not going to do our best to attempt to do so, but it means it is going to be difficult. That is why I have focused everyone to say, let us look at the budget process first, because that is where the determination really is going to be made as to how far we can move the funding forward.

Let me ask you a question. First, let me say that I visited an inner-city community health center in Chicago last year, and as I passed a television screen, there was the National Library of Medicine's Medline right there. And what you say about the availability of the latest technology and procedures to everyone in the health care services community, it really is true. They are doing wonderful things, and we are great fans of the National Library of Medicine.

We have provided increases for NLM larger than the ones that they have asked for, but you are telling me that they need to increase their staffing. Does Dr. Lindberg agree with that? He has got the money to do so if he thinks he needs an increase in staffing, or at least we think he does. Would he agree that he needs more staffing?

Ms. Puckett. Yes. He does. I think that they were still--perhaps some of the funds that belong to some of the other programs, the HPPC, the initiative in working with that issue, they are still looking for more staff because of the increase in load.

What the National Library of Medicine is actually taking on with all this increase of services, to do this, we need more and more people there so that a good job can be done and we can stay with the same level of excellence that you, and other Members of this Congress and the people at large know of what NLM does for them.

Mr. Porter. Perhaps that will then be reflected in the President's budget figure for NLM this time. It has not been reflected in the past, obviously, and we have attempted to give them all the resources that they possibly need within their capabilities of doing that. We will certainly take a look at it and see if we can do a better job.

Ms. Puckett. Thank you.

Wednesday, January 28, 1998.

WITNESS

DAVID WHISTON, AMERICAN DENTAL ASSOCIATION

Mr. Porter. Dr. David Whiston, the president of the American Dental Association.

Dr. Whiston. Nice to see you, Mr. Chairman. Thank you very much for the opportunity.

As you mentioned, I am here as the president of the American Dental Association and also as a practicing dentist across the river in Arlington, Virginia, although our headquarters are in Chicago, as you know.

Certainly, with the passage of the State Children's Health Insurance Program, some Medicaid changes over this past year, I think we can safely say it has been the year of the child relative to health care in general, particularly relative to oral health care, and I certainly want to acknowledge the work that the subcommittee has done, you in particular, in enhancing support for issues of prevention and research and education.

We think there are new opportunities this year, and we would specifically like to address the segment of the population that classically seems to fall through the cracks as these issues develop.

Particularly in our field, we see about 25 percent, primarily of needy kids, who have over 75 percent of the tooth decay, the dental decay, that we see and treat in our offices every day. So we want to try and focus on that group.

I would like to just, again, touch on three broad areas where we feel that that focus should take place, and, again, that is prevention, research, and education.

On the preventive side, certainly the maternal-child health block grants, where you have been extremely supportive relative to the SPRANS activity, trying to enhance community water fluoridation initiatives, then as those initiatives develop and continue to outreach to the States and it is necessary for implementation, we certainly would speak for enhanced support of the Division of Oral Health within CDC; not only for fluoridation but also for, for example, other preventive measures, really proven, cost-effective measures such as placement of dental sealants, and we see that sealant utilization is just a touch under 30 percent. So we would like

to see certainly increased activity there.

Beyond prevention, I think we quickly enter into the research area, and research for us primarily means National Institutes of Dental Research; certainly need for increased support relative to the dental and craniofacial issues, that they continue to be on the cutting edge of research there but also, for example, some of the dramatic links we are seeing now between periodontal disease on the one hand and low birth weight infants on the other, periodontal disease and cardiovascular disease. Some of those issues really need increased research.

On the education front, just to briefly touch on four particular items under that heading, certainly the general dental residency program, with particular emphasis on pediatric training, because that is where the greatest shortage is in the dental prevention; loan repayment programs, where received practitioners go to underserved area; the Ryan White HIV/AIDS reimbursement program; and, finally, the minority and disadvantaged programs. Those four areas, in particular under education, we would like to speak for enhanced support.

All of these have been proven cost-effective ways of addressing deficiencies in the specific target areas. And certainly we realize, given all the testimony that we have heard, as you have heard today, that you have very difficult decisions to make with finite resources. We would ask for your continued great personal support for these particular areas: Prevention, research, education.

Thank you for this opportunity to appear before you.

[The prepared statement of David A. Whiston follows:]

[Pages 439 - 446--The official Committee record contains additional material here.]

Mr. Porter. Well, Dr. Whiston, we very much appreciate your testimony. All of the areas that you have touched on are obviously priorities. The difficulty, as you point out, with our subcommittee is that there are so many important priorities, I think, for people under our jurisdiction. I won't repeat my sermonette again, but it is really where we must get some progress. And if we can, then we can address each of these areas in an even more forceful way than we have in the past.

Dr. Whiston. We really, obviously, appreciate the dilemma and, again, certainly appreciate the great support that you have given our profession, but health care in general over the years. We really appreciate it very much.

Mr. Porter. Off the record, I think that they ought to provide a perk to the president of the American Dental Association and allow you to spend a year in our great City of Chicago.

Dr. Whiston. I would like that. I have tried to find ways, but they seem to like citizen soldiers in our profession, so I will continue to practice.

Thank you very much.

Mr. Porter. Thank you so much for appearing, for your testimony.

The subcommittee will stand in recess until 10:00 a.m. tomorrow.

Thursday, January 29, 1998.

WITNESS

ANNA STREET, NATIONAL JOB CORPS COALITION

Mr. Porter [presiding]. The subcommittee will come to order.

I have to remind witnesses that there are two provisions in the House rules that they must be aware of, and I'm talking about nongovernmental witnesses. In addition to their written statement, they must submit a curriculum vitae and a statement of Federal grant or contract funds that they or the entity they represent have received. If you have any questions about these rules, and whether they apply to your situation, or how to comply, please contact the subcommittee staff.

I will also warn all the witnesses that the staff has a new innovation this year. Tony, why don't you hold that up? He's getting very tough on the time, and he'll be timing witnesses. The reason for it is that we have 200-plus public witnesses, and even at that, we are not able to accommodate all those people who wanted to testify. So we're going to have to be pretty strict about our five-minute time limit, and I think you're already probably aware of that.

With that, our first witness is Anna Street, Center Director at Partners in Vocational Opportunity Training, testifying in behalf of the National Job Corps Coalition.

Ms. Street.

Ms. Street. Thank you very much. Thank you. Chairman Porter, members of the subcommittee, it's a great honor for me to speak before you today on behalf of Job Corps. As some of you may know, Job Corps gave me my second chance. I graduated from the Tongue Point Job Corps Center in 1968. I sit before you as a testimony of what Job Corps can do for a young man or woman with the determination and perseverance to take advantage of all that this program has to offer.

Every day I see not only what the program can do for young people, but what Job Corps represents to them. It is a beacon of hope in an otherwise hopeless life. The PIVOT Job Corps Center is a pilot site of the Springdale campus located outside of Portland, Oregon. PIVOT stands for Partners in Vocational Opportunities Training and was established as a pilot in 1989. PIVOT is a specialized campus in that we serve exclusively young mothers and provide onsite child care for their children. Although to many people these young women are statistics, they aren't to me. They're young people with dreams just like you and me. Job Corps represents the only way for many to make these dreams a reality today. Let me tell you about these dreams.

They are not about wealth or fame. They are about down-to-earth values we've all been taught to treasure--a home, a family, a good job to make it happen. We take this for granted, but for the young people that go to Job Corps this is what keeps them going: the knowledge that through Job Corps they have a chance.

Your support for this program has been instrumental to

many. Your continued support for operational funds for Job Corps is indispensable. However, ever-increasing demands on our operational budget are made every day.

Since 1993, every contract center's operational budget has been under a mandated ceiling of 3 percent a year. Much of Job Corps' services are noncontrollable costs such as food, clothing, medical services, utilities, and health insurance. Any cost increases greater than 3 percent are taken from controllable costs: staff, salaries, and wages. Generally, even city, county, and State governments allow between 5 and 6 percent.

Since 1993, we've added many student services requiring additional highly-qualified staff, such as the implementation of zero tolerance policies and the institution of a 13-week follow-up program to ensure that our students are successful once placed on jobs. Mr. Chairman, Job Corps is a labor-intensive program. Each human life entrusted to us is individually guided through the program. Thus, the quality of services delivered to these young people, as well as their ultimate success, is greatly dependent upon the capabilities and quality of the staff caring for them. If we jeopardize the quality of our staff, we jeopardize the quality of our program and our product, which is to produce taxpayers, wise consumers, good parents, good employees, and, yes, future leaders.

Diminishing numbers of staff at the national and regional levels affect the program's ability to oversee the increased services required by our students, as well as the expenditure of funds this committee entrusts to the program. I ask the committee to see what more can be done by the Department to ensure adequate coverage and oversight of Job Corps.

The committee has supported the need to replace, repair, maintain, and build Job Corps centers. Just this past year, $4 million was appropriated to start the process of incremental expansion. For that, we in the Job Corps community are truly grateful.

As you know, the need for Job Corps has not abated. From my experience, there are ever-increasing numbers of young people that can benefit from this particular program. Mr. Chairman and members of the committee, you can make the difference, and you do. Your continued support for the establishment of new centers, satellites, and pilot programs like the PIVOT program, is critical if we're going to keep pace.

Each new slot that you fund at a new campus represents a human investment, an investment in the health of our communities, free from poverty, drugs, and crime. And you know this is true because Job Corps proves itself with results year after year.

Last year the committee also asked that the repair and maintenance process on centers be somehow expedited. I couldn't agree with you more and applaud your efforts in this area. There needs to be a cost-effective and time-efficient process established, possibly de-centralizing this activity at the contracting and administrative levels. There has to be a better way to ensure that centers don't remain on long waiting lists without knowledge of when repairs will happen.

We've talked about the need to adequately fund and expand Job Corps. However, I've found that through my years in the

program that if child care were available more extensively throughout the program, many more young parents, particularly young women, could take advantage of this second chance.

Mr. Chairman, you and the members of the committee, recognized the importance of child care last year when you instructed Job Corps and Head Start to seek ways to work together. I agree. There needs to be a partnership between these two organizations.

Currently, Job Corps has 19 child care facilities on 19 campuses nationwide out of 115 centers. Most of these programs, like PIVOT, are offered as a service to nonresidential students, students who do not live on campus. They provide child care services for single parents enrolled in Job Corps, and I can tell you from my own experience in Oregon, young, economically-disadvantaged----

Mr. Porter. If you can finish----

Ms. Street [continuing]. Oh, okay--disadvantaged women face seemingly insurmountable challenges in daily life. So your support for this Job Corps program, which really does continue to serve young at-risk people, and help work in collaboration with welfare-to-work, school-to-work programs and continues to work with placing them in the workplace, it's very, very important.

I thank you for this opportunity to testify before you today, and I ask that you remember that you've been given the power to make these dreams come true. Please remember Job Corps and the lives of its young people, their dreams, and their successes, because you often do--you really do--make the difference.

Mr. Porter. Ms. Street, one of the things that you--all of the things you said, but particularly one of the things that you said struck me as absolutely critical for everything that we are privileged to fund. You said Job Corps proves itself with results.

Ms. Street. Yes, sir.

Mr. Porter. The money we invest in Job Corps proves itself in the lives of young people, and they are, in respect to our society, probably the most at-risk young people of all. We are great fans of Job Corps.

Ms. Street. Thank you, Chairman Porter.

Mr. Porter. As you probably are aware, in 1995 when we were required to make huge cuts in our budget, there were 10 programs that we did not cut; one of them was Job Corps.

Ms. Street. Thank you.

Mr. Porter. Because we believe in it. The restraints which you're working under are restraints that exist in the law, so we can't do anything about that, but we can put it at the high priority that it deserves, and we will do our best to do that.

Ms. Street. Thank you, Chairman Porter.

Mr. Porter. Thank you for the wonderful job that you're doing.

Ms. Street. Thank you. It's a pleasure.

[The prepared statement of Anna Street follows:]

[Pages 452 - 457--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

DAVID HYDE PIERCE, ALZHEIMER'S ASSOCIATION

Mr. Porter. Our next witness is David Hyde Pierce. He is the co-star of the NBC series ``Frasier.'' We're delighted to welcome ``Niles'' to our table. [Laughter.]

I told him a minute ago that my wife, Catherine, and I have an opportunity to watch just two shows on television, in addition to the news, and one of them--and we are absolute regulars--is Frasier. So we're delighted to have you here, Mr. Pierce, and you're going to be testifying on behalf of the Alzheimer's Association.

Mr. Pierce. Yes.

Mr. Porter. Mr. Stenny Hoyer.

Mr. Hoyer. Thank you, Mr. Chairman. I want to join you in welcoming ``Dr. Crane'' to the table. [Laughter.]

Phyllis, I thought maybe you were representing ``Dr. Crane'' in your other hat with psychiatrists, but we're glad to have you here.

Mr. Chairman, I have the opportunity to participate in press opportunity this morning with Mr. Pierce, a distinguished actor, as you know, a graduate of Yale, and he and his sister, Nancy, are here with us. He has a compelling story to tell. I said this morning that I was always very pleased that people who are celebrities, and therefore can focus attention on issues, some obviously spend their timefocusing the public's attention on what I would call the insubstantial--I guess that's as kind a word as I can choose for it--and some others, being a celebrity allows them to focus their attention on compelling issues concerning our society. Obviously, David Pierce is one of the latter, and we very much appreciate, Mr. Pierce, you and your sister being here. I know the committee looks forward to hearing your compelling story.

Thank you, Mr. Chairman.

Mr. Pierce. Thank you. I just have to say I'm honored to be here; I'm also a little apprehensive. I played John Dean in a movie a couple of years ago--[laughter]--and sitting in front of you all, I'm having terrible flashbacks. [Laughter.]

But I'm here for a good cause, so I'm going to push through.

Mr. Chairman, members of the subcommittee, I'm here on behalf of the Alzheimer's Association, but I'm really here on behalf of my family and the millions of families like mine across America. My grandfather died of Alzheimer's disease, and I was trying to think of a way to explain to you how awful that was, how devastating that was for my entire family, when I had the terrible realization that I probably don't have to explain it to you because Alzheimer's disease is now so widespread that every one of you knows someone, a family member or a friend, or a former colleague who is suffering with this disease. And so you already probably feel, as I do, that I cannot bear to see someone I love go through this ever again.

That is why I'm here today, to ask you to invest an additional $100 million in Alzheimer's research at the National

Institutes of Health to launch an immediate, all-out Alzheimer's disease prevention initiative, and I want to emphasize ``immediate'' because there is a time issue here. Researchers are telling us now that Alzheimer's disease begins attacking the brain cell by cell as much as 20 years before the onset of the symptoms we all associate with the disease. By the time the symptoms occur, it's too late; so much of the brain is destroyed, nothing can be done--20 years. That means that half of us in this room who may get Alzheimer's have that time bomb ticking in our heads right now.

Four million Americans suffer from Alzheimer's now. If the disease goes unchecked, by the baby-boomers, our generation, reach the age of maximum of risk, 14 million Americans will suffer from the disease. Every one of them will lose their memory, their judgment, their ability to perform basic daily tasks. Every one of them will require full-term care. That care would be mostly provided by their families, and their families will be bankrupted emotionally, physically, and financially by that. I think that alone is enough for a compassionate nation to launch an all-out war on this disease.

But there's another very compelling reason for Congress to do something now, and that is: you cannot save medicare and medicaid if you let 14 million baby boomers get Alzheimer's disease. Medicare spends 70 percent more on a beneficiary who has dementia than on one who doesn't, and almost half of medicare patients who have Alzheimer's also use medicaid because they've gone through all their resources, spending on average $47,000 a year on the long-term costs that medicare doesn't cover. So medicare and medicaid can't survive the onslaught of this disease.

There's one more aspect of the time element that I want to convey. As there is a lag between the onset of the disease and the onset of symptoms, there is also a lag time between the beginning of research and the fruits of research. Now in the early nineties, Congress doubled funding for the Alzheimer's research of the National Institutes of Health. We are now today, this year, seeing the results of that investment with incredible discoveries every week coming out NIH-supported laboratories. The problem is, since 1992, funding has leveled off, and it's not keeping pace with the scientific opportunities. Scientists now know what they need to do in order to find a cure for this disease, and there isn't enough money at the NIH for them to do it. They have discovered simple treatments, like vitamin E and ibuprofen, which may slow or stop the progress of the disease, but they need to do large-scale clinical trials in people my age to find out whether that's really an effective cure. They have to find clear biological markers, so we can identify people at risk, and treat them before the symptoms occur and it's too late. They have to develop laboratory models to check the progress of the disease and come up with more effective treatments.

Finally, while we're researching a cure, we have to find better and more cost-effective ways to treat the people suffering from the disease for whom a cure will come too late. If we don't do this now, we will lose another generation, our generation, to this disease.

For my family, for all of our families, I urge you to

invest $100 million in Alzheimer's research at the National Institute of Health, and please do it now, because time is running out. Thank you very much.

Mr. Porter. Mr. Pierce, three years ago, we had before this subcommittee as public witnesses a woman who was probably in her--she might have been 50 or 51 years old. She came and sat at the table there, and talked about her husband, who sat next to her. He had been a decorated Navy pilot and had then had a career as a test pilot following that, and she said that Alzheimer's came upon him at a very young age. He did not any longer know her most of the time, and he was maybe 55 years old. And she said, think about, if you will, with our life expectancies, we're going to have the rest of our lives in this situation, and what that devastation will do to each of us and our families and our children. I think that deeply touched--it certainly did me--every member of the subcommittee.

This subcommittee puts biomedical research funding at the very highest level. I said a moment ago that there were only 10 line items out of 800 that we raised three years ago when we had to make severe cuts to work toward a balanced budget. In that context, when the Budget Committee was suggesting we cut NIH 5 percent per year for five years, we raised NIH 5.7 percent. The year before last, 6.9 percent; last year, 7.1 percent, and I can assure you that this is absolutely one of the highest priorities that this subcommittee has--of any.

We don't fund by disease, but we do fund by institute, and we don't direct science, but we sure do tell them what our priorities are. I think that you'll find that this subcommittee shares your deep concern and has, I hope, an understanding of the devastation that this disease causes, and, in addition, understands the opportunities that are there if we can reach out for them and provide NIH the resources that they need.

So my promise to you is that we will do our very best to try to get those resources to NIH and have that job done.

Thank you.

Mr. Hoyer.

Mr. Hoyer. Mr. Chairman, thank you very much.

I know the committee--and to everybody in the audience, you had no prepared statement; you, obviously, in the first place were impacted by this, but as I pointed out at the beginning, not only are you personally affected, but taking that experience and, obviously, versed yourself in knowing what this is about and what can be done. Thank you very much for your dedication. Certainly on behalf of your grandfather, if you hadn't gone through the consequential impact of the Alzheimer's disease on your grandfather and your mother and her sister, which obviously devastated them, as well as your grandfather--it is compelling testimony.

Mr. Chairman, I'm going to have to leave. I apologize for that. I have another hearing--as you know, we have multiple hearings in multiple committees--that I need to do.

As I look behind me, you would be amazed, I want to tell the witnesses, I had a fellow on loan from the Secret Service. There's a program of exchange. He was here and he sat in this room, and most of the time I wasn't here because I was in other hearings. I'm the ranking member on another committee. He said he learned more in the three months of hearings than he had

learned in a lifetime. He was in his forties. So that these folks back here [referring to staff] are listening intently, and they are very compelling when they come back and tell us about the testimony. I'm always, Mr. Chairman, I know as you are, concerned that we can't all be at two or three places at the same time, so we could listen to the very compelling testimony, like David's, but so many others who are going to testify after.

Thank you, Mr. Chairman. I thank all of you.

Mr. Porter. Can I add one thing? Stenny said that it's important that people who are in the public eye, celebrities and the well-known, stand up for the things that are important to them and important to all Americans. I admire someone like you who comes up and lays before us your family's problems with this disease and catches the attention of the public and focuses on something that's so important to every person on the planet. So thank you for coming here to testify today.

Mr. Pierce. Thank you.

Mr. Porter. We very much appreciate it.

Mr. Pierce. Thank you, Mr. Chairman.

Mr. Porter. Thank you, Mr. Hoyer.

[The prepared statement of David Hyde Pierce follows:]

[Pages 462 - 467--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

ROBERT WILSON, WILSON ASSOCIATES

Mr. Porter. Our next witness is Robert Wilson, Wilson and Associates, testifying in respect to neurofibromatosis. Mr. Wilson.

Mr. Robert Wilson. Thank you, Mr. Chairman, for the opportunity to present testimony on the need for a continued Federal commitment to research for neurofibromatosis, also known as NF, a terrible genetic disorder closely linked to cancer, brain tumors, and learning disabilities affecting over 100 million Americans.

I am Robert Wilson, president of Wilson Foundation. My 11-year-old son, Michael, suffers from a severe case of NF. I have been working for many years with NF groups from around the country, the growing NF scientific community, Members of Congress, and the National Institutes of Health. I appear before you today on behalf of Michael and the 100,000 other Americans who suffer from NF, as well as the tens of millions of Americans who stand to benefit from NF research.

As a result of your support for biomedical research, each year that I appear before your subcommittee I bring exciting news of a breakthrough in NF research that moves us closer to a treatment and cure for this terrible disease. Once again, I'm able to report to you a major breakthrough since last year which holds promise not only for the individuals suffering from NF, but also for the 100 million Americans who also suffer from

NF-related diseases.

Last spring, researchers at Cold Spring Harbor Laboratory and the Massachusetts General Hospital in Boston have determined for the first time that the NF gene in the fruit fly is linked to learning and memory disabilities. The studies show that the protein made by the NF-1 gene is part of the pathway which is known to control learning and memory, while at the same time still being implicated with NF's cancer-fighting tumor suppressor functions. The major breakthrough leads to new opportunities for drug and genetic therapies for NF patients, experiments which have already begun on the fruit fly. Cold Spring Harbor Laboratory stated in a recent newsletter that NF research stands to benefit ``a vast segment of the human population, including those afflicted with learning disabilities, Alzheimer's disease, and other dementias.''

NF, incorrectly, but commonly known as the elephant man disease, involves the uncontrolled growth of tumors along the nervous system which can result in terrible disfigurement, deformity, deafness, blindness, brain tumors, cancer, and even death. It is the most common neurological disorder caused by a single gene.

Dr. Samuel Broder, former Director of the National Cancer Institute, stated that NF was at the ``cutting edge'' of cancer research. This cancer connection was at the heart of two major conferences on NF held in October 1995 and July1997 at the Cold Spring Harbor Laboratory in New York, one of the world's leading cancer and neuroscience research laboratories headed by James Watson, the co-discoverer of DNA. These conferences brought together basic researchers, clinicians, biotech, and pharmaceutical companies from around the world to find a treatment and cure for NF. After the first conference, more than 20 leading NF researchers worked for over one year preparing a detailed blueprint for finding a treatment for Nf. This document has been well received at NIH and many researchers are calling for this document to be used as a model for how NIH should fund further research.

The enormous promise of NF research is its potential to benefit tens of millions of Americans in this generation alone. It has gained increased recognition from Congress and the NIH. For Fiscal Year 1999, I encourage the subcommittee to support the following four-part NF research agenda, which expands upon the advances made to date:

One, increase appropriations for NIH. Sustained growth for the NIH is necessary to seize the tremendous opportunities brought about by previous research successes built past scientific achievements, address present medical needs and anticipate future health challenges. Toward this end, I encourage the subcommittee to support the recommendation of the Ad Hoc Group for Medical Research Funding, which calls for a 15 percent increase in the NIH budget for Fiscal Year 1999. This represents the first step toward doubling the NIH budget over the next five years.

Two, increase appropriations for NF research. In addition to holding the promise of improving the lives of tens of thousands of individuals who suffer from NF, recent research has demonstrated that NF research stands to benefit the 100 million Americans who suffer from cancer, brain tumors, and learning disabilities. Therefore, I urge the members of this

subcommittee to increase funding for NF research at NIH.

Three, continue cooperation and coordination between NCI and NINDS through targeted NF research programs. In your Fiscal Year 1998 report, the subcommittee encouraged NCI and NINDS to coordinate efforts and to pursue an aggressive program in basic and clinical research. I applaud NCI and NINDS for the coordination that has occurred to date, and encourage the committee to continue to urge the continued expansion and the coordination for NF research.

Four, target funding for the implementation of the clinical research initiatives generated at the Cold Spring Harbor Conference. As developed by Cold Spring Harbor Laboratory at its NF conference in October 1995, NF should become the model for scientist-initiated proposals to fund clinical treatment research for specific diseases which offer the potential for significant advances in broader areas, such as tumor suppressor genes.

In closing, Mr. Chairman, with only a small investment, dramatic advances in NF research have been made with far-reaching implications for many other diseases. Many of the world's leading NF researchers now believe that, with an increased investment, and a research agenda focused on all aspects of the NF research portfolio, from basic research in the labs, to drug development and genetic therapy, a treatment and cure for NF can be found in the next few years.

I would like to end with a statement that appeared in a recent edition of the Cold Spring Harbor Laboratory newsletter which focused on major breakthroughs in NF research. The hope is that the day may come when doctors can flip critical switches to repair the broken circuits in each of these disorders. Such life-changing therapies will be the reward for years of enthusiastic basic research. I believe, Mr. Chairman and members of the subcommittee, that with your continued support, that they will soon be here.

Thank you.

Mr. Porter. Mr. Wilson, thank you for your testimony and for your working to draw attention to this disease, and to come here to urge us to direct more funds toward biomedical research. You are going to get my sermonette, but it's for the whole audience.

Mr. Wilson. Right.

Mr. Porter. And that is that I think that the desire to bring as much resources as possible to bear on biomedical research exists on this subcommittee. It's a high priority for us. The difficulty will be that in order to even think in terms of an increase in magnitude in that program or other programs outside of biomedical research under the jurisdiction of this subcommittee, we are going to have to have a budget allocation large enough, obviously, to accomplish that. The budget allocation comes through the budget process, which is under the jurisdiction of our Budget Committee in the House and the Senate. That's where the first action that could set the basis, the foundation, for the kinds of increases that the ad hoc committee is talking about occurs. So, in a sense, you're preaching here to the choir.

Mr. Wilson. Sure.

Mr. Porter. But don't overlook the need to also talk to

members of the Budget Committee and tell them that this is a high priority for this country, and that we need the kind of allocation that will allow us to do the kinds of things that you and other witnesses have suggested and the ad hoc committee has strongly promoted.

So we're willing. Give us the resources, and we can do great things, but we need help in getting those resources.

Mr. Wilson. Right.

Mr. Porter. I have to lay that sermonette on every witness group.

Mr. Wilson. No, I agree with you, and I think if the members of the Budget Committee were to go up to NIH and meet with some of the heads of the NCI and NINDS, and so forth, they would see the enthusiasm that they have----

Mr. Porter. Assuredly.

Mr. Wilson [continuing]. And the breakthroughs that they are making on a daily basis. And they are so excited. They feel like this is ending a man to the moon. They are making--they have so much enthusiasm, and they're really predicting that treatment and cures are closer and closer.

Mr. Porter. If you're focused on dollars--and we must be--there isn't a better investment because it repays itself in health care costs saved in the future----

Mr. Wilson [continuing]. Absolutely, absolutely.

Mr. Porter. So many times over. If we can focus the Budget Committee on those two things, I think you're exactly right. So we're going to work on that. We hope you will also.

Mr. Wilson. Yes, and as an example, my son has learning disabilities, and it's costing the school system an additional $60,000-$70,000 a year alone for one child.

Mr. Porter. Exactly.

Mr. Wilson. Those are big dollars for a school system to spend on a number of kids that obviously have a lot of different learning disabilities.

Thank you.

Mr. Porter. Mr. Wilson, thank you so much.

[The prepared statement of Robert Wilson follows:]

[Pages 472 - 477--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

DR. NICOLE LURIE, SOCIETY OF GENERAL INTERNAL MEDICINE

Mr. Porter. Our next witness is Dr. Nicole Lurie, MD, president of the Society of General Internal Medicine; professor of medicine at the University of Minnesota, testifying on behalf of the Society. Dr. Lurie, welcome.

Dr. Lurie. Thank you. Good morning, Mr. Porter, members of the subcommittee, and your staff. Before I go into my prepared remarks, I'm going to ask you to step back for a moment and imagine yourselves 10 years from now, sick with a chronic illness, maybe even Alzheimer's disease. You have a lot of life

ahead of you, and you want to spend as little of it as possible in the hospital. You're being cared for by a doctor who is being trained today. But that doctor hasn't been taught to care for your special needs in a home or outpatient setting, and worse yet, doesn't have at his or her disposal the best evidence about the most appropriate treatment that will lead to the best outcome for your disease. That's a real scenario, and one that will occur unless we fund AHCPR and title VII programs at a level that will let them do their jobs.

I'm pleased to be here today on behalf of the Society for General Internal Medicine, an organization representing the nearly 3,000 physicians who are primary care, internal medicine faculty of every medical school and major teaching hospital in the United States. SGIM members prepare medical students, residents, and others to be primary care doctors for the 21st century, and they conduct research that improves patient care.

Let me talk first about health professionals' training. As you know, medical practice has changed drastically over the last two decades, moving from a primarily hospital setting to the outpatient arena, and it will change even more in the next 10 years. Unfortunately, our primary way of funding graduate medical education--that is, through medicare--provides little support to train outside the hospital. This is a major impediment to training physicians who are prepared to practice in current and future environments and manage the ever-growing population of patients with chronic illness that we're hearing about.

This funding mechanism only works well if we want to train most doctors to practice in the past; I don't think we do. General internal medicine/pediatrics title VII programs provide the major source of funding for primary care training, permitting us to train health care professionals for the 21st century, and to train them to care for underserved populations, which will in all likelihood still be with us.

SGIM is particularly proud of the track record of title VII-supported general internal medicine grant programs. Over 69 percent of HRSA-funded internal medicine program graduates go on to primary care practice after graduation--nearly twice the rate of internal medicine programs without title VII funding. Over 40 percent of internists trained through title VII-supported have established practices in medically-underserved communities in the past two years. You should know that the appropriation for general internal medicine programs in Fiscal Year 1998 was insufficient to permit the funding of new or competing renewal applications. While we recognize that your support has allowed these programs to survive at all, we urge you to fund title VII at a level that actually lets it get the job done.

Let's shift gears for a moment and talk about AHCPR. As you probably know, the Agency for Health Care Policy and Research is one of three science agencies in the Federal budget that are necessary to maintain and improve the health of our Nation.

We've just heard a lot about NIH, and the NIH budget is necessary to bring laboratory-based knowledge that will someday be translated to clinical application at the bedside. The CDC provides the science for public health. Despite this, you and I hear all the time the cries of alarm at the state of our health

care system, and there's a serious disconnect here.

It's the AHCPR that supports the discovery of new knowledge that can improve the health care system and can identify the highest quality, most cost-effective ways to getscientific breakthroughs into the health care delivery system in America. Yet, is it an agency that is seriously underfunded.

Just like at the NIH, some of the best work comes from investigator-initiated programs, but inadequate funding means that the AHCPR can support only a very small handful of individual investigators. Many, like myself, no longer even bother to prepare grant proposals for the AHCPR because the funding prospects are so bleak. Since 1994, the AHCPR has cut the number of funded investigator grants by over 50 percent. Ultimately, this translates into denied opportunities for the American public, and for you, the Congress, to make wise policy choices and save money. It may mean that we don't have the evidence to best treat your problem ten years from now, and will have to rely on anecdote instead.

On a positive note, let me give you a couple of examples of recent research released by the agency, because it is this type of research that both improves quality of care and cuts health care costs, that a funding increase could support.

Middle ear infection is the most frequent diagnosis requiring antibiotics for children in the United States. AHCPR-supported research at the University of Colorado found that common ear infections in children with less expensive antibiotics, instead of more expensive ones, could save millions of dollars a year without changing recovery rates. The study estimated that in one State alone, and one program alone, the Colorado medicaid program could have saved almost a half million dollars by implementing this change in treatment.

Research supported by AHCPR also leads to the development of new technology that can be applied to make the functioning of the health care system more efficient. Recently, a tool to predict whether someone with chest pain is actually having a heart attack has been shown to reduce unnecessary coronary care unit admissions by 30 percent. This translates into 250,000 fewer critical care admissions a year, keeping people out of the hospital, and about a $3 billion savings per year in the U.S.--by all standards, a great return on investment.

Mr. Chairman, our funding recommendations for the title VII internal medicine/pediatrics programs is for $25 million for this year. This will allow for some growth within the program, but it will take closer to $50 million if you are really serious about getting the job done in the future. Our recommendation of $306 million for the entire title VII program reflects the recommendations of the Health Professions and Nursing Education Coalition.

For the AHCPR, we will ask you to provide the funding necessary to repair the damage done over the past three years to the investigator-initiated grant program and to the training program. We recommend an AHCPR budget of at least $175 million, a $32 million increase. But, remember that in just one year example I've shown you how a modest investment translates into a gigantic cost-saving, in this example, of up to $3 billion. I think it's a great example of fiscal responsibility.

I'd like to close by thanking you and your subcommittee for

the strong support of the title VII programs and the AHCPR in the past. I look forward to your continued support in the future. I'd be pleased to respond to any questions. Thank you.

Mr. Porter. Dr. Lurie, thank you for your testimony.

Regarding AHCPR, you're probably aware that there are a few detractors in Congress on AHCPR, and that became a major issue about two-and-a-half years ago----

Dr. Lurie. Yes.

Mr. Porter [continuing]. And we felt that we had done a good job in getting them the resources that they ultimately were allocated. I think your testimony is exactly right, AHCPR does a wonderful job, and in the process it's bound to gore a few oxes that perhaps need goring. We ought to pay very close attention to the work that they do and give them adequate resources to do their job. So I think you're exactly right, and we'll do our best to both of those, both title VII and AHCPR.

Dr. Lurie. Good. Thanks. As I'm even listening to this testimony this morning, I'm struck time and time again of how much promise there is and how much we need to separate out the promising things that actually work from the promising things that stay as promise in the future, and I think that's AHCPR's job. Thank you.

Mr. Porter. I think you're right.

[The prepared statement of Nicole Lurie follows:]

[Pages 481 - 494--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

DR. JOSEPH HOBBS, ORGANIZATIONS OF ACADEMIC FAMILY MEDICINE

Mr. Porter. Dr. Joseph Hobbs, M.D., president of the Society of Teachers of Family Medicine and associate dean of primary care at the Medical College of Georgia, testifying in behalf of Organizations of Academic Family Medicine. Dr. Hobbs, welcome.

Dr. Hobbs. Good morning.

Mr. Porter. Good morning.

Dr. Hobbs. Mr. Chairman, I'm Joseph Hobbs, M.D., associate dean for primary care at the Medical College of Georgia and president of the Society of Teachers of Family Medicine. I appreciate this opportunity to speak in support of critical funding of family medicine training and research.

Mr. Chairman, this committee has been very supportive of health professions training in general and family medicine training in particular. We appreciate that support and hope that you will be able to sustain your efforts in the coming Fiscal Year. We ask that you continue to value family medicine training made possible by title VII funding, which helps to support an educational infrastructure that produces family physicians--these flexible, well-trained physicians whose broad-based training makes them especially qualified to serve in rural, innercity, suburban, and other settings, responding

to the primary care needs of all populations.

The organizations of academic family medicine have asked this committee to support these programs at a new authorized appropriated level of $87 million for section 747, family medicine training. There's good justification for this funding level because section 747 has facilitated the recent successful establishments of departments of family medicine in many medical schools. Third year required family medicine clerkships which we know influences the choice of primary care now exist in many more medical schools as a result of these programs. The vast majority of the residency training grants last year in family medicine met the funding preference to service the underserved, thus meeting congressionally-mandated health care service goals.

Our recommended funding level is the result of a strategic plan developed by the academic family medicine organizations to maintain the production of family physicians needed to increase primary care access to all Americans. We further recommend the combined authority of $306 million for all health professions programs, equivalent to the amount this subcommittee and the House passed last year.

In another measure of success, a GAO report stated that title VII was considered important in the creation and maintenance of family medicine departments, individuals, and medical schools. Another report stated that students who attended schools with adequately funded family practice departments and those with third year family medicine clerkships were more likely to pursue primary care careers.

Title VII has helped build much of this needed family medicine training infrastructure. A number of years ago my institution was awarded an innovative training grant to develop an academic community partnership with a network of rural clinics in a four-county health professions shortage area which was economically depressed and unable to attract and keep private physicians. That grant contributed to the development of set of self-sustaining rural clinics which now serve as teaching sites for residents and students who provide care, along with teaching physicians, to a population in need. This rural health exposure of family medicine residents has also resulted in the successful recruitment of many of our graduates to practice in these and other rural communities throughout our State.

Mr. Chairman, some argue that since medicare, GME funds, residency training through GME, there is no need for title VII funding. This is not the case. Medicare GME funding is directed to hospitals to defray the basic cost of training residents. Most of the title VII family medicine funding is directed at medical schools to help develop the primary care infrastructure in those institutions. Only one-third of the Nation's family medicine residents receive title VII funding, which, unlike the GME funds, goes to programs to develop innovative curricula, linkages with community training opportunities, faculty development, and to maintain the fiscal stability of those departments of family medicine.

Studies underway indicate that the ratio of rural physicians to population, which has been declining steadily, is increasing for the first time in a half century. This change is

almost entirely the results of an increased number of family physicians, which decreases the current rural physician shortages. However, sustaining these efforts is dependent upon adequate funding of family medicine training programs, of which title VII resources have been a critical part.

Also of great concern to the academic family medicine is funding of the Agency for Health Care Policy and Research, or AHCPR, which has a mandate to support primary care and practice-oriented research. We ask that, as you contemplate expanded levels of support for the NIH, that you include AHCPR in that support. While our country has invested in basic medical science research through NIH programs, there has been little support to develop clinical applications of these new basic science findings. In order to support the critical practice-oriented primary care research, we ask at least an additional $25 million be targeted for the Center for Primary Care Research at AHCPR.

In closing, I would like to express my sincere thanks to this subcommittee and to Chairman Porter and to Congressman Bonilla in particular, who have championed health professions funding, and request your continued support and efforts.

Mr. Porter. Dr. Hobbs, thank you very much for your testimony.

You're absolutely correct, Henry Bonilla has been a very, very strong advocate of the health professions, and I think the House has done a fairly good job of providing resources there.

This is just a word of advice, but I think we have to concentrate on the U.S. Senate on this one. [Laughter.]

When we go to conference, if their number is very low and ours is good, Dr. Lurie and Dr. Hobbs, you know, we don't necessarily end up at the stronger number. We will do our best. Henry has been a tireless advocate for the health professions, and I think that we'll have a decent opportunity within the limits of our allocation to do that here, but we need a little help on the other side of the rotunda.

Dr. Hobbs. Thank you, sir.

Mr. Porter. Thank you, Dr. Hobbs.

[The prepared statement of Dr. Joseph Hobbs, M.D., follows:]

[Clerk's note:--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 498 - 503--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

BRUCE BAGLEY, AMERICAN ACADEMY OF FAMILY PHYSICIANS

Mr. Porter. Bruce Bagley, M.D., board member, American Academy of Family Physicians, representing the Academy. Dr. Bagley, thank you for being with us.

Dr. Bagley. Good morning, Chairman Porter. My name is Bruce Bagley. I'm a family physician from Albany, New York, and a member of the board of directors of the American Academy of Family Physicians. I appreciate your ability to move me on the schedule to follow Dr. Lurie and Dr. Hobbs because I think you're going to hear some very similar themes. We also have concerns about health professions funding and research.

On behalf of the 85,000 members of the American Academy, I'd like to speak to you this morning about three issues that are important to our patients. First is appropriations for section 747 of the Public Health Service Act for family practice training. Second is appropriations for the Center for Primary Care Research at the Agency for Health Policy and Research, and, finally, funding for rural health programs.

I also want to thank the subcommittee, and particularly Mr. Bonilla and yourself, for your support in the past for higher funding levels for the health professions.

The academy strongly supports increased funding for section 747. It is the only Federal program that provides targeted funding for family practice training programs. We urge you to appropriate $87 million to section 747.

There's a shortage of generalist physicians. While most countries have at least a 50/50 split between generalists and subspecialists, the United States physician workforce is made up of more than 70 percent subspecialists and only 30 percent general physicians. Health planners believe that a physician workforce of at least 50 percent generalists and 50 percent specialists would best meet America's health care needs. Medicare policies currently provide incentives for hospitals to train physicians in subspecialties that are already in oversupply.

Family physicians are needed to care for the everyday health problems of the American people. A study conducted by KPMG Peat Marwick in September of 1995 reported that medicare spending could be cut by at least $49 billion, and possibly as much as $270 billion, over the next six years if today the ratio was 50/50 for primary care. Family physicians are distributed in the urban and rural areas in the same proportion as the U.S. population as a whole. Even so, 149 counties in this Nation, represent 550,000 individuals, have no physician.

Our track record is clear in this regard. Over 90 percent of physicians who complete family practice residency programs go on to provide frontline care for the citizens of this country where they need it.

Section 747 works, as you've already heard. Funding for pre-doctoral programs under section 747 encourages medical schools to create required third year clerkships in family medicine. Clerkships are important because they expose medical students, who are mostly trained in hospitals, to real community practice.

The American Academy of Family Physicians also strongly supports a primary care research agenda within the Agency for Health Care Policy and Research. The U.S. health care system has little emphasis on cost-saving preventative care. We see limited medical resources being consumed trying to rescue people from long-term illness or poor health habits. While American medicine is praised worldwide for its excellence in

biomedical research, we have often failed to translate these breakthroughs into practical treatment that will apply to all patients.

As you consider increases for the National Institutes of Health, and hear President Clinton's call for greater NIH funding, we ask that you also consider more dollars for AHCPR. This research will help me to better care for you and your family. The Academy requests that $50 million in additional appropriations be provided to AHCPR to support this crucial line of research.

Finally, the Academy supports increased funding for rural health programs to ensure that all rural Americans receive the same health care as urban dwellers. These appropriations will allow more of our citizens to have a personal physician to provide the care they need when they need it and where they need it. As family physicians, we care for America, and we need your help to attract and train young physicians for this important work.

Thank you.

Mr. Porter. I very much appreciate your testimony, Dr. Bagley. I think your point that, regardless of what we develop, if it can't be brought to people, it doesn't do any good at all, is a very, very good one, and we certainly will take that into account in marking up this bill and trying to do the best that we can to fund the programs that you have testified in behalf of.

Dr. Bagley. I'd like to follow up on Dr. Lurie's point that the rubber meets the road where the physician and the patient are in the doctor's office or in the community, and we really don't know whether many of the things that we're taught to do in medical school work well or not, or work as well as they could. So we're very anxious to see some good quality primary care research to help us do a better job every day.

Mr. Porter. Thank you so much.

[The prepared statement of Bruce Bagley, M.D., follows:]

[Pages 506 - 516--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

MARK WILSON, REPRESENTING HIMSELF

Mr. Porter. Mark Wilson, the Rebecca Luckens Fellow in Labor Policy at the Heritage Foundation, testifying in his own behalf. Mr. Wilson.

Mr. Wilson. Thank you, Mr. Chairman and members of the committee, for inviting me to testify on the appropriations for the Department of Labor. I'd like you to please accept my written testimony and enter it into the record. It should also be noted that my following testimony is my own view and does not necessarily reflect that of the Heritage Foundation.

In Fiscal Year 1998, the Department of Labor's discretionary budget authority was $11.3 billion. The largest

portion of this, two-thirds, went to employment and training programs. In response to requests from President Clinton, Congress has substantially increased spending on these programs over the past two years. Since Fiscal Year 1996, for example, the appropriations for the adult training has increased 25 percent; summer youth training has gone up 39 percent; spending on programs for dislocated workers has increased 23 percent. Just last year, Congress also approved a new welfare-to-work program that will spend an additional $3 billion over the next three years.

Yet, despite these huge increases, and the best labor market conditions in the country in the past 25-30 years, the President intends to ask for even more spending on jobtraining programs in Fiscal Year 1999. This year, before Congress appropriates any more funds for job training programs, it must ask itself a fundamental question: Why should we continue to spend taxpayer money on programs that don't work?

The few rigorous studies that have ever been done thus far show either a record of failure or disappointingly small and fleeting benefits that don't justify the cost of the program. Even worst, many agencies do not know if their programs are even working or not.

Reforming the current Federal job training system must involve more than just consolidation, which the House has recently passed and the Senate is going to consider this spring. Job training programs must be rigorously evaluated at every level, Federal and State, to ensure that future tax dollars that will not be squandered on equally ineffective programs.

Congress and this committee should also exercise its authority under the Government Performance and Results Act to ensure that the Department of Labor includes a number of control group evaluation studies of job training programs that it administers in its strategic plan.

Over the past 30 years, thousands of local job training programs, as well as hundreds of billions of dollars have been spent. Yet, only a few dozen job training programs have ever been subject to rigorous evaluation. The few studies that have been conducted generally show a failure--or generally fail to show any significant long-term increases in hourly earnings directly related to the training. A comprehensive study published just this last December in The Journal of Economic Literature concluded that there is a lack of compelling evidence that skills-building activities in these programs have actually enhanced the skills of the participants that are of value to employers.

The only group helped by these programs apparently is adult women, and then only by a modest amount. The results for every other group, adult men and youth, are either nonexistent or negative.

In another study, Professor James Heckman at the University of Chicago concluded from his research that, zero percent is a much closer approximation to the true rate of return of these Federal job training programs than the 10 percent that the administrators profess they do.

The General Accounting Office, sadly--again, most agencies cannot even verify whether their programs are working, let

alone keep track of the people that are in them. The U.S. General Accounting Office in 1995, for example, found that almost 40 percent of Federal job training programs could not accurately count how many people they served each year, and most programs lacked outcome data. Less than 50 percent of the programs collected data on whether or not the participants obtained jobs after they completed the job training program, and only 26 percent collected data on the wage that those people earned. Only a handful of programs knew whether participants would most likely achieve the same job placement outcome without the program.

Despite the eloquent testimony of Anna Street earlier, a 1995 GAO study was unable to verify the job placement of 15 percent of the Job Corps sample that they had looked at, and found that over 22 percent of the Job Corps students dropped out of the program early. The high cost of the program, over $16,000 a year per student compared to $7,000 per year for a public college--that's room and board and tuition--and these disturbing results raise serious questions about whether or not Congress should continue to spend hard-working taxpayer dollars on this ineffective program.

As Congress begins to focus its attention on reforming Federal job training programs, it should consider implementing a few common-sense solutions to improve the effectiveness of these programs for both the participants and the taxpayers. We need to implement control group evaluation studies, rigorous performance measures at the State and national level. These types of studies will tell Congress and the States and the taxpayers which programs are working and which ones are not. Those we find that do work, we should take a look at whether they can be expanded. Those that don't should be eliminated. We need to close down the programs that don't work, and we need to vigorously implement--Congress should vigorously implement--the Government Performance and Results Act.

Thank you.

Mr. Porter. Mr. Wilson, let me agree with a great deal of what you said. In fact, the focus of this subcommittee since I've been chairman has been results for people. If you can't get results in your program for people, why are we funding it?

We have sent a letter this year to each of the Secretaries of the three departments over which we have jurisdiction and also all of the agencies over which we have jurisdiction, and told them that their testimony must focus on how their programs are working for people or not. That's exactly where we will be this entire hearing cycle.

We have also invited GAO to come in to testify in respect to the programs in each of the three departments separately, and to lay out for us exactly what their view is of the success or lack of success in the programs under consideration.

You, I think, are correct in saying that there's a lot of priority in the White House that differs from the priorities in the Congress, and when you come down to the finalanalysis, there's give and take in the conference, what will the President sign or what will he not sign, that we don't get a product that is necessarily just our view. We do the best, however, that we possibly can. The careers legislation has passed in the House of Representatives.

Mr. Wilson. That is correct.

Mr. Porter. I believe it is not passed in the Senate yet.

Mr. Wilson. That's correct.

Mr. Porter. And if it is passed, that will change the whole outlook, I think, for job training programs and make them a lot more efficient and a lot easier to evaluate, since there will very most certainly be a lot fewer of them to start with. So I think we share all of those goals.

I will say, in respect to the Job Corps, that it is a high-cost program per individual, but it takes kids who come from places where drug use and crime and poverty is at its highest and brings them out of that atmosphere into an entirely different environment, one that many of them have never experienced before, and puts a good deal of them on a path that they would otherwise have no chance of reaching. I think under those circumstances we look at Job Corps in the same--what results are you getting?--as any other program, but I think we have to understand, in respect to that one at least, that there is a different set of circumstances, and there is a value to hope. There is some value to hope for people. It may cost more, but if we can get results, if we can take those kids out of those environments and put them into a work environment where they keep a job, raise a family, put their kids on the right track, I think we've probably achieved a lot.

Clearly, we share let's get results for people. I don't know when you were in here; you must have been here when Ms. Street testified, and I said to her, the line that you talked about proves itself with results; that's exactly what we're looking in every single Federal program, every single line item that we fund, we're looking for results. So we share your philosophy on that, and we'll do the best we can to achieve them.

Mr. Miller.

Mr. Miller. Thank you. I'm glad you're here today because we have very few people that raise questions. What studies are being done outside of the Department of Labor questioning the effectiveness and success of these programs? Maybe we need resources more into that. I know we require them to document their efforts.

Mr. Wilson. Some States are currently looking into the prospect of conducting their own studies. Texas is one, for example. There are a number of other States that are looking into the possibility of conducting their own control group evaluation studies to determine whether their programs that they run that are funded in part through JTPA currently are effective.

Most of the studies that have ever been done, and even the studies that are currently being done, have some Federal funding behind them in order to do them. These are not inexpensive studies to conduct. They're not expensive compared to the amount of money that we're spending, and the results that we have seen from these studies so far indicate that a lot of this money is being spent ineffective, and perhaps we should be evaluating. If we evaluated more programs, we could find those few that are working and build upon those, and more effectively spend our taxpayer dollars.

But there are no independent studies outside of the

Department of Labor or for the States that are currently being conducted in this area.

Mr. Miller. Thank you. Thank you, Mr. Chairman.

Mr. Porter. Thank you, Mr. Miller. Thank you, Mr. Wilson.

Mr. Wilson. Thank you, Mr. Porter.

Mr. Porter. We appreciate your testifying.

[Prepared statement of Mark Wilson follows:]

[Pages 521 - 529--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

TERRY-JO MYERS, INTERSTITIAL CYSTITIS ASSOCIATION

Mr. Porter. Terry-Jo Myers, Interstitial Cystitis Association national spokesperson, testifying in behalf of the Association. Ms. Myers, we're delighted to welcome you back----

Ms. Myers. Thank you.

Mr. Porter [continuing]. To our witness table. We're also delighted that you won twice last year on tour. That was very exciting. I'm a great fan of the LPGA. In fact, I have tickets already for the open at Black Wolf Run----

Ms. Myers. Fantastic.

Mr. Porter [continuing]. Up in Wisconsin. I have a son that happens to live about 25 miles away from there. So I'm going to be there the whole week.

Ms. Myers. I could have gotten you tickets.

Mr. Porter. Yes. [Laughter.]

Ms. Myers. Maybe I couldn't have.

Mr. Porter. Exactly. [Laughter.]

Ms. Myers. You just buy them.

Mr. Porter. Well, let me say one other thing. We understand that you're going to receive the Ben Hogan Award this year.

Ms. Myers. Well, you're spoiling my whole speech.

Mr. Porter. I shouldn't talk about that?

Ms. Myers. No, go ahead. [Laughter.]

Mr. Porter. Well, we just think that that is absolutely wonderful. We understand that they weren't going to award this award this year because of Ben Hogan's death, but that the comeback that you have achieved in overcoming this disease and getting a chance to exhibit your talent has turned them around, and that you're going to receive this award at the Masters' Tournament.

Ms. Myers. Yes.

Mr. Porter. So we congratulate you on that. We're delighted to have you back before our subcommittee to testify, and we wish you tremendous success on the tour this year.

Ms. Myers. Thank you. Thank you. I hope I don't sound repetitive now.

Again, thank you for giving me the opportunity to present my testimony here today. I would like to tell you about interstitial cystitis and ask you for continued funding of research to find a cure for this painful and debilitating

disease.

My name is Terry-Jo Myers, and I am a professional golfer, completing my 13th year on the LPGA tour. I also have IC.

While today and every day I appear healthy to anyone who meets me, that is because the effects of interstitial cystitis are not visible to others. I can, however, assure you that my work, my family, and social life, and my pursuit of my dreams, have all been dramatically affected due to IC.

Many of you may already know that my IC story has a happy ending, for I have been able to find relief. I'm here to give a voice to all those IC patients who are still too ill to leave their homes and cannot speak to you today.

Interstitial cystitis is a chronic, inflammatory bladder condition. Its cause is unknown and there is no uniformly reliable treatment. The symptoms, which can be severe and unrelenting, include urgency and frequency of urination, up to 60 times in 24 hours, and pain in the bladder. And the pain I describe, it feels like I would have had papercuts lining my bladder wall. It was quite painful.

I was diagnosed with IC shortly after I developed symptoms at the age of 21, and I was told that nothing could be done. Doctors said, I would just have to learn to live with the pain, and that's the prescription that far too many IC patients still receive.

Every step I took was painful, and for a tour player it was torture. Often, I could not even bend down to line up a putt. I would have to go to the bathroom as often as 50 times a day, including 15 to 20 times a night. I played in nonstop pain, and had constant anxiety about being able to make it to the next bathroom. Because travel is especially difficult for many people with IC, I would often arrive at tournaments exhausted; my friends would be out playing their practice rounds, and I would often be forced to remain in the locker room.

The saddest of all for me personally is that IC has affected my golf game. As a junior athlete, I won many tournaments, but as a professional with IC, my performance was terribly hindered by the disease. Because LPGA rules prohibit players from leaving the course for any reason, I had to withdraw from many tournaments in the middle of a round because I needed to get to a bathroom. In 1988, I won the Mayflower Classic, but I attribute much of that win to the fact that we had two rain delays in the final round that allowed me to get to the bathroom and keep playing.

I'm very happy to report that last season, as you've already mentioned, I did win the Los Angeles Women's Championship, as well as the Sara Lee Classic, finishing the season with over $300,000 in earnings, and I attribute much of that success to the oral drug Elmiron, which was recently approved by the FDA for marketing. Unfortunately, Elmiron provides relief in only about a third of the IC sufferers who try it.

For me, last year was a dream come true. My story appeared in many newspapers and magazines across the Nation. I was featured in People magazine. I appeared on countless television shows to share my story of success.

The most gratifying result of all this publicity beyond my own sense of achievement was the fact that the Interstitial

Cystitis Association, the ICA, was able to reach out to more IC sufferers than ever before.

In mid-December, I received the Heather Farr Award at the LPGA 1997 awards luncheon. This award, voted on by tour players, recognizes a player who demonstrates determination, dedication, and spirit through the game of golf. Heather Farr, who was a close friend of mine, died of breast cancer in 1993 at the age of 28. As I told The New York Times, I never told Heather that I had IC, but watching her fight cancer helped me to continue my fight against IC. She fought her battle very public, and she was never angry or bitter, and I guess I just borrowed some of our strength. For that reason, that award is especially meaningful to me.

And as if that weren't enough gratification for any athlete, earlier this month I did receive a letter from the Golf Writers' Association of America indicating that I had been voted the Ben Hogan Award. This award is presented annually to someone who has continued to be active in golf, despite a physical handicap or serious illness. This beautiful bronze statue of Mr. Hogan has been awarded to such golf heroes as Ken Venturi, Lee Trevino, and President Eisenhower. I will be attending the awards dinner in Augusta on Wednesday, the eve of the Masters' Tournament in April.

Although I am immensely grateful for my reclaimed success, there are many, many others who have not been as fortunate. I have had IC for 14 years. It's been only six years since I was able to find a doctor to help me. This doctor has put me in touch with the ICA and motivated me to take steps to begin to cope with my illness. This doctor was also aware of Elmiron and made sure that I was able to take the Elmiron.

Not all IC patients can say this. Many can't travel, work, or meet their family obligations, and many become financially destitute as they lose their health insurance coverage and try to keep up with their IC treatment. Some have their bladders removed, only to encounter a whole array of medical problems.

My success story is not one that all IC patients can claim, and that is what motivates me the most. Because it is comparatively a rare disease that affects mostly women, and historically neurology and neurological research have focused primarily on male urological problems, interstitial cystitis is a disease that continues to be ignored by many members of the medical community. It is serious and it can be costly.

An epidemiological study, sponsored by the Urban Institute, found that an estimated 450,000 people in theU.S., men and women both, may suffer from IC, with an economic impact as high as $1.7 billion per annum.

Fortunately, there is hope. Thanks to previous congressional funding, the NIDDK built the IC database, an extensive pool of IC patient information collected at nine sites around the U.S. and stored and analyzed at the Pennsylvania State University Hershey Medical Center. The researchers have already begun to publish reports analyzing data obtained from this study, with the expectation that the database will provide clues as to how IC develops and to diagnose and categorize patients and how to treat their disease more effectively. In short, the database has provided the first systematic, long-term look at a large number of IC sufferers.

Thanks to your support, the IC database is now moving into phase two, which will test and study new treatments for IC. The Interstitial Cystitis Association and all IC patients are very grateful to all members of this subcommittee, and in particular, to Chairman Porter and Congressman Bonilla, your ongoing support, your support of the IC research and other urological diseases. Without your help, we would be nowhere in our struggle. Because of your commitment, we are beginning to see some progress.

In conclusion, to continue this research initiative, we request that the committee provide additional funds to the urology program of the NIDDK in Fiscal Year 1999 to be used for expanding the variety of investigators doing research on IC. These funds should be used to support further research specifically into IC. Proposals should be solicited through a series of requests for applications, RFAs, for individual research grants and pilot studies which would look into, one, new strategies for IC symptom relief; two, epidemiology, and, three, further understanding the basic science of IC.

The committee requests that the NIDDK prepare a report of ongoing research studies and areas for research solicitations, demonstrating where advances can be made in the effective treatment and prevention of IC. We still have far to go; yet, we are confident that with your help, and with adequate continued funding for IC research through the NIDDK, results will be no less than miraculous.

As a victim of IC, I know what it is like to endure the chronic, unrelenting pain, and please help us to end this suffering and help us to find a cure for this horrible disease.

Mr. Porter. Thank you for coming to testify before our subcommittee once again. We had earlier this morning David Hyde Pierce. I don't know whether you got a chance to see him. That's Dr. Niles, Frasier----

Ms. Myers. No.

Mr. Porter [continuing]. Co-star of the Frasier series. We said to him that people who are in the public eye, celebrities like yourselves, really do a wonderful service in focusing this country on these kinds of problems. He testified on Alzheimer's disease which affected his family.

I want to commend you for standing up and riveting public attention on this disease and what we can do to help other people that have it.

Ms. Myers. Thank you.

Mr. Porter. Obviously, you don't have to do that, but you're making a difference in others' lives, and we appreciate that very much.

Now should Casey Martin be able to ride in the cart or not? [Laughter.]

Ms. Myers. Yes, I think he should be able to ride in a cart, absolutely.

Mr. Porter. Is that the feeling on the tours, that that's okay?

Ms. Myers. I would go out on a limb and say that is the feeling of the players, yes. If he is good enough to play golf on a professional level such as the PGA tour, I would never deny him the right to play.

Mr. Porter. Then why shouldn't you have been allowed to

leave the course?

Ms. Myers. I was not as smart as Mr. Martin. I did not think about that. However, it's a very interesting situation, his lawsuit.

Mr. Porter. Yes.

Ms. Myers. I will follow it.

Mr. Porter. It's ready for trial or starting trial very soon, is it not?

Ms. Myers. February 2.

Mr. Porter. Yes, yes.

Ms. Myers. Yes.

Mr. Porter. Mr. Bonilla.

Mr. Bonilla. I'd just like to, very briefly, second what the chairman said about your appearance here and your appearance in previous years, you as a person. It's admirable that you're what you're doing and taking all this time. You've got a lot of success now. You could be doing a lot of other things, working on your game, traveling around the country----

Ms. Myers. I do need to do that.

Mr. Bonilla [continuing]. And I know that's important, but the fact that you take personal time as a volunteer to come here to help those that may be affected in the future by IC is really a testament to you as a person. I just think that should be pointed out again.

Ms. Myers. Thank you. I will never let myself forget the pain and all of the anxiety, that I lived with thisdisease for the 11-plus years that I was in so much pain. If I allow myself to forget that, then I may not take the responsibility I need to take with this disease.

Mr. Porter. Ms. Lowey.

Mrs. Lowey. Thank you, Mr. Chairman. I want to join our chairman and my colleague in welcoming you here, and associate myself with the remarks that you've heard, how important it is to be an advocate. I want to particularly welcome a constituent of mine, Laurie Fishfein, who is also here, whose daughters have suffered greatly from the disease.

We're aware that this does affect primarily women----

Ms. Myers. Yes.

Mrs. Lowey [continuing]. And we join you in your optimism that we can end in the pain, we can find a cure, we can prevent the suffering that so many people go through.

I just want to assure you that there is a great deal of support in this committee, and that your personal testimony and that of Mrs. Fishfein and others does make a difference. We are often pulled in so many different directions, and I am very pleased that there seems to be in this Congress, in this country, great support for the National Institutes of Health.

Ms. Myers. Yes.

Mrs. Lowey. We can assure you that we're going to work to increase those dollars, increase the dollars for research for this disease, and we thank you again for your participation here this morning.

Ms. Myers. And thank you for your tremendous support. Thank you.

Mr. Porter. Thank you, Ms. Lowey.

Now have you played the River Course at Black Wolf Run?

Ms. Myers. No, but I've watched the Anderson Consulting

Match Play. I've watched it very carefully.

Mr. Porter. Well, you'll love this course, and it might be a great place to win your first U.S. Women's Open.

Ms. Myers. That would be fabulous, and remember, you bought the tickets.

Mr. Porter. I did; I'll see you there. [Laughter.]

Thank you so much for being with us.

Ms. Myers. Thank you, Mr. Chairman. Thank you.

[The prepared statement of Terry-Jo Myers follows:]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 536 - 540--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

ERIN BOSCH, PRIVATE CITIZEN, REPRESENTING HERSELF

Mr. Porter. Erin Bosch, a private citizen, testifying in her on behalf. Ms. Bosch, it's nice to welcome you back again.

Ms. Bosch. Thank you.

Mr. Porter. Thank you for testifying.

Ms. Bosch. Mr. Chairman, members of the subcommittee, I'm honored to have the opportunity to speak to you today. My name is Erin Bosch, and some of you may recall that I addressed you last year on behalf of the National Coalition for Heart and Stroke Research. Today, I'm here to represent not only myself, but the 32,000 children in the United States who are born with congenital heart defects.

Most of us are aware that heart disease is the No. 1 killer and a leading cause of disability in adults in this Nation, but few recognize that heart defects are the most common birth defect of the newborn. Of the 32,000 children born each year with heart defects, around 2,300 die before their first birthday. The rest of us live with the consequences of heart disease, and many have their lives cut short from heart failure.

Thanks to past funding for heart research, about 1 million Americans who were born with heart defects are alive today. While we are grateful for each day to be alive, we, unlike other healthy children, have not been able to experience what it's like to run the length of a soccer field without struggling for our next breath, nor have we experienced the thrill of running down the basketball court to score the winning basket.

I was born with genetic heart disease, called hypertrophic obstructive cardiomyopathy. This disease has caused the heart muscle to overgrow and block the flow of blood in and out of my heart. It also affects the valves of my heart, causing the blood back up in the wrong direction. This diseases causes high risk for heart attack and sudden death from dangerous heart

rhythm.

One year ago in October, I was at the Mayo Clinic having open heart surgery. This procedure, called a septal myectomy, is designed to shave away a portion of the heart muscle that causes the obstruction. This procedure was originally pioneered at NIH's National Heart, Lung, and Blood Institute, and was my last resort, aside from transplantation.

It is funding that this committee has provided that has allowed this type of successful research. Without this funding, my option of a healthier lifestyle would not have been possible for me. I'm one of the lucky ones. My surgery was successful, and after one month at Mayo, I was able to return home.

There have been some advances for children like me, although many still die prematurely. Most people think heartdisease is a problem that only affects older people, but I'm living proof they are wrong.

According to recent studies, 36 percent of young athletes who die suddenly have undiagnosed hypertrophic cardiomyopathy. Presently, there are at least 35 different types of recognized congenital heart defects affecting the newborn population. Some can be corrected surgically; others cannot yet be repaired, and these children die. One of these children might one day be your child or grandchild.

I have great faith in the determination of our scientific researchers who work day and night to find new treatment methods for those who suffer with illness or disease. I also have great faith in you as doorkeepers of governmental funding for the National Heart, Lung, and Blood Institute to provide the necessary funds for children who, through no fault of their own, have been born with heart defects.

Thank you for the opportunity to speak to you today. I'm confident that you will not forget me and the other young people like me who depend on you for funding for this vital research. We, too, desire to live long and productive lives.

Mr. Porter. Ms. Bosch, thank you for your very compelling testimony, and I think I can assure you, on behalf of the whole subcommittee, that we definitely will not forget you and other young people, and we'll do our very best to put this funding into high priority and to make the kinds of increases that can really make a difference in people's lives in the future.

Thank you for coming here to testify.

Ms. Bosch. Thank you.

[The prepared statement of Erin Bosch follows:]

[Pages 543 - 545--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

JUDITH DESARNO, NATIONAL FAMILY PLANNING AND REPRODUCTIVE HEALTH ASSOCIATION

Mr. Porter. Judith M. DeSarno, president and CEO, National Family Planning and reproductive Health Association,

representing the National Family Planning and Reproductive Health Association.

Ms. DeSarno. Good morning. My name is Judith DeSarno, and I am the president and CEO of the National Family Planning and Reproductive Health Association, a nonprofit membership organization dedicated to promoting and protecting access to family planning and reproductive health care for all women, men, and their families.

Thank you, Chairman Porter and members of this subcommittee, for affording me the opportunity to testify before this subcommittee. I would like to concentrate my remarks on increased funding for title X, our National Family Planning Program.

This program was founded 27 years ago to help lower unintended pregnancy rates and the lower the incidence of infant mortality and morbidity. I am here today with good news: that the rate of unintended pregnancy in the United States has begun a well-documented decline. According to the latest data analysis from the Alan Guttmacher Institute, the rate of unintended pregnancies fell by 16 percent between 1987 and 1994. This drop has been attributed largely to higher contraceptive prevalence and the use of more effective methods of contraception. The decline in unintended pregnancies has also lowered the abortion rate. This is all very good news. Family planning works. One can only wonder how much greater a decline there would be if every woman who wished it were able to have access to affordable, reliable contraception.

The administration will be affirming its commitment to title X by requesting an additional $15 million for the program in its Fiscal Year 1999 budget. While title X has received small increases in recent years, thanks in large measure to your leadership, Mr. Chairman, and the strong support and leadership of Mrs. Lowey and Ms. Pelosi, funding has not kept pace with inflation or need. If title X funding had kept pace with inflation since 1980, it would today be funded at almost $500 million instead of its current funding level of $203 million.

Unfortunately, health care costs did continue to rise. For example, in just the last five years, the cost of oral contraceptives, the most popular method of reversible contraception in this country, has tripled for virtually all title X clinics.

If one patient desires Depo-Provera, an IUD, or Norplant, the most effective and long-lasting contraceptives, many other patients may go unserved because of the high cost of these methods.

Title X family planning professionals are being asked to do more with fewer resources. The increase of $15 million would allow us to provide many more women and men with family planning services; expand outreach efforts to reach hard-to-reach populations such as the homeless and the drug-addicted; expand weekend and evening hours to make services more accessible to patients; expand programs to involve males, who, after all, are half of the equation; provide more screening and treatment for sexually-transmitted diseases.

Family planning works. We know that postponing that first birth beyond the teenage years and allowing families to space

their children is the most important precursor to healthy children and families.

We know that increased access to contraception is bringing down the unintended pregnancy rate and the abortion rate.

We also know that we must all work together to lessen the need for abortion. I am here today to urge this committee to join all people concerned with the health of women and their families--abortion supporters and abortion opponents alike--to join us in making sure that all women have the opportunity to plan their pregnancies.

Mr. Chairman, we have the dramatic news this morning that there was a bombing at a women's clinic in Birmingham today with at least one person dead. We must end the violence. Wemust stop demonizing personal choices, and we must work together to find preventive measures.

Thank you.

Mr. Porter. Ms. DeSarno, thank you for your testimony. I couldn't agree with all of it more. It is good news that unintended pregnancies are down in the United States. It would be even better news if they were down all across the world.

Ms. DeSarno. I think it's important to note that the United States still has, in the industrialized nations, the highest unintended pregnancy rate. So we're not really----

Mr. Porter. We're not there yet.

Ms. DeSarno [continuing]. Doing enough in this country either.

Mr. Porter. I've just learned of a new program called Educate America that has enlisted Charlton Heston, Edward James Olmos, Morgan Fairchild, and others, and is intending to bring the message of the importance of family planning and contraception back to the American people, where it seems to have been missing for such a long time. Are you aware of this?

Ms. DeSarno. I am not aware of it. That's very good news, Mr. Chairman.

Mr. Porter. Well, I think it is the kind of thing that is really needed. In my judgment, there is a concerted all-out attack on family planning that in a way hides behind the issue of abortion that I think is unrelated. Abortion is not an acceptable method of family planning, in my judgment. Contraception is what we should emphasize, and yet we have got these issues bound together, very unfortunately. I think that those who believe that family planning is a personal human right for every father and mother and family really have to focus on this, and this Educate America program seems to me to be a way to do that.

Edward James Olmos is a personal friend. He's stood up for many causes that he believes in, including innercity kids who are highly at risk in our society, and reached out to them. I think this kind of leadership from celebrities--we've had a couple of celebrities here today--but I think it can make the difference in respect to family planning as well, and I would urge you to give them all the support you possibly can.

Ms. DeSarno. Oh, absolutely. We know that the American people, by an enormous percentage, support family planning. Ninety percent of Americans polled say they support family planning, and a majority also support Federal funding for family planning.

For years, I have felt that we need to undemonize or take out of the political rhetoric family planning. I know that Members of Congress often reflect where they think their constituents are. Their constituents strongly support family planning, and it seems like a step in the right direction. Title X is there ready to serve all those many women who have no access to family planning, if we can get that funding up.

Mr. Porter. Looking at how close the votes have been on title X indicates that the message isn't getting through from the constituents to the Members. We've got to do a much better job of that.

Ms. DeSarno. I absolutely agree.

Mr. Porter. Thank you for your testimony this morning.

Yes, Ms. Lowey.

Mrs. Lowey. Thank you, Mr. Chairman, and I just want to associate myself with your remarks, and thank you for coming before us today. I'm particularly pleased that you emphasized that family planning works.

I do hope, Mr. Chairman, that those of us who are pro-choice, those of us who are anti-choice, can unite and work together to focus on the importance of family planning. You mentioned, and I'd just like to emphasize again, that family planning reduces the need for abortion. Whether one is pro-choice or anti-choice, we all agree that we have to reduce the need for abortion.

I know in this committee many of us are focused on increasing investments in contraceptive research, providing access to women to contraceptives, so they can plan their own families. I'm also hoping that the responsibility of other committees--that we can all work together to make sure that the insurance companies provide coverage for contraceptives if, in fact, they provide coverage for other prescription drugs.

So the focus should be on contraceptives, family planning, and I am cautiously optimistic that we can convince our colleagues to continue to increase our investment in contraceptives and family planning, because this really has to be the key to preventing unintended, unwanted pregnancies.

I thank you again for your important work. We look forward to working with you.

Ms. DeSarno. Thank you, Ms. Lowey. No one has done more on the complete answers to preventing unintended pregnancy than Mrs. Lowey, and I salute her for that.

If we'd had longer than five minutes, I have a statement of increasing to $20 million research for contraceptive research. We must--the challenge for all of us, pro-choice or anti-choice, is to work together to lessen the need for abortion. I think it's a moral imperative for all of us.

Thank you.

Mr. Porter. Thank you, Ms. DeSarno.

[The prepared statement of Judith DeSarno follows:]

[Pages 549 - 557--The official Committee record contains additional material here.]

Mr. Porter. This subcommittee will stand in recess for five

minutes.
[Recess.]

Thursday, January 29, 1998.

WITNESS

SUSHMA D. TAYLOR, CENTER POINT, INC.

Mr. Porter. The subcommittee will come to order.

Sushma D. Taylor, Ph.D, executive director, Center Point, Inc., representing Center Point, Inc.

Ms. Pelosi. Mr. Chairman.

Mr. Porter. Oh, I'm sorry, Ms. Pelosi. I'm sorry.

Ms. Pelosi. Thank you, Mr. Chairman. Mr. Chairman, before I introduce our next witness, I did want to mention, for your comments about the title X--it seems a long time ago, but it was five minutes ago, the previous witness. Following up on that, I was very encouraged by your remarks, and of course they are a reflection of the great leadership that you have demonstrated on this issue, both domestically and internationally. So as a member of your committee, once again, I'm proud of you as my chairman----

Mr. Porter. Thank you.

Ms. Pelosi [continuing]. And I thank you very much for your very, very unequivocal and strong statement in support of family planning.

I also appreciate the opportunity that you are allowing me in welcoming and introducing Dr. Sushma Taylor, a CEO at Center Point. Dr. Taylor's program serves the San Francisco Bay Area and specializes in substance abuse treatment services for women and children, the homeless, adolescents, those with HIV, including some involved in the criminal justice system.

Dr. Taylor has long been a pioneer in the field of treatment. As one who believes that treatment is a very appropriate route for us to go to reduce demand in our country, demand for doing drugs in our country. I appreciate and support her approach, and I am pleased to welcome here today, on behalf of the committee, Dr. Taylor, and we look forward to your remarks.

Thank you, Mr. Chairman.

Mr. Porter. Thank you, Ms. Pelosi.

Ms. Taylor. Thank you, Ms. Pelosi. That's extremely generous, gracious, as ever. You've been such an advocate for women and for the dislocated, for the poor, and on behalf of all of them, I thank you for your continued work.

Ms. Pelosi. Thank you.

Ms. Taylor. Mr. Chairman, thank you for the privilege of being here today. I serve as the CEO at Center Point, a provider of comprehensive health, social, vocational services to high-risk families and individuals. I also appear on behalf of my colleague, Dick Steinberg, president of WestCare, who provides programs in Nevada and California and Arizona.

Our programs offer treatment and rehabilitation that interrupt abusive addiction cycles. Our organization, in existence for 28 years, has expanded, and we currently serve 5,000 clients per year in diverse health, social, addiction,

treatment, and vocational services.

Center Point and WestCare both believe that there's extraordinary potential in the most ordinary person, and our clients visibly demonstrate that change is possible and that adversity can be overcome. The clients we serve overcome domestic violence, homelessness, sexual abuse, unemployment, substance use disorders, and infectious diseases such as tuberculosis and the devastating HIV/AIDS. They become proud, productive members of our community.

We have, Mr. Chairman, that the President's Fiscal Year 1999 budget request for SAMHSA may contain a $200 million increase. Center Point and WestCare respectfully ask that this additional funding be shared between the substance abuse block grant and the knowledge development application program, thereby enabling the expansion of innovative approaches to treatment.

We would like to emphasize that the KDA efforts are worthwhile, and they refine our understanding of what works in controlled treatment settings. An investment in knowledge development and application will work to enhance cost-effectiveness of the entire substance abuse treatment field.

You're interested in studies and results. In 1997, the Center for Substance Abuse Treatment revealed the entire study of 5,700 clients one year after treatment. There was a 55 percent reduction in drug and alcohol use, a 77 percent decrease in violent crime, a 19 percent increase in employment, and an 11 percent decrease in welfare costs. Treatment pays; it pays great dividends.

We also believe in the development of educational, vocational, and interpersonal skills that we encourage in our programs. We hope that you, through your committee, will charge the Department of Labor to continue to provide vocational assessment and job training for people who make the difficult transition from welfare to work.

We encourage the subcommittee to engage the Department of Labor and Education to work with community-based organizations which have successfully infused employment-related skills into their treatment programs, and also as they begin to design welfare-to-work curriculums.

Another one of our goals is to provide cognitive behavioral and psychosocial skills which are aimed at enhancing personal responsibility. The National Center on Child Abuse and Neglect has recognized the role that parental substance abuse and domestic violence can play in child abuse and neglect. Domestic violence and treatment programs need to be an essential component to any effort to improve the quality of life for all of the families that are afflicted by substance abuse and concomitant disorders. We ask thesubcommittee to encourage the Administration for Children and Families to engage agencies such as the CDC to continue to fund demonstration projects that recognize the correlation between substance abuse and domestic violence.

We further urge the committee to engage programs such as the Bureau of Primary Health Care's health care for the homeless program, because these programs allow homeless individuals to access primary health care needs in a more cost-effective manner than emergency rooms. They need to stabilize their health conditions before they can engage in treatment.

Finally, Mr. Chairman, Center Point and WestCare are pleased that the National Institute on Health is beginning to reconsider research protocols and that now the grant review procedures will be based on the quality of the science and the impact that it might have on the field, rather than on the details of technology or methodology.

Mr. Chairman, Ms. Pelosi, on behalf of WestCare and Center Point, thank you for this opportunity. But more than that, we thank you on behalf of the families we serve for your leadership, your generosity, your dedication. Your actions do make a difference in the lives of the most dislocated people in our communities, but also those who have hope because of your leadership. We hope that you will continue to fund these programs that make them become productive human beings.

Mr. Porter. Dr. Taylor, thank you very much for your testimony.

We have a facility in my district in Waukeegan, Illinois that sounds very similar to your Center Point facility. There's others, and of course I have visited it and seen the good work that it does for people that have tremendous problems in their lives and get involved in drugs and see no way out. There's other programs in Chicago that I visited also, and they are apparently very similar to what you do. So we, I think, understand the importance of this funding.

In the President's budget, the increases in discretionary funding are largely supported by proposed revenue increases mostly--not solely, but mostly--coming from the tobacco settlement. The difficulty, of course, is going to be: are we going to see a tobacco settlement this year? Is that going to be in the budget? I think, very frankly, it's a wonderful idea, particularly in reference to health care and health research funding, to have our tobacco industry share more in those costs and would be supportive. But I don't know that this is ever going to materialize. So we're going to have to see whether these problematical revenue increases are going to be there, and in the meantime, we're going to have to do the very best we can within the resources we actually are allocated, whatever they may be, to prioritize.

That's another short sermonette for today, but I think we've got to put the thing in perspective.

Ms. Taylor. We know that funding is tight, and we also know that you have difficult choices and conflicting needs. We just ask you to remember with your hearts the people that do suffer, as you do every year, and as you make those difficult choices.

Mr. Porter. Thank you so much.

Ms. Pelosi.

Ms. Pelosi. Thank you. In the interest of time, I will be brief, Mr. Chairman, but I appreciate your interest in Dr. Taylor's testimony.

Dr. Taylor, I'm sure you realize that $200 million in the current budget environment is a great deal to request. Can you briefly give just a little justification as to why that figure is the appropriate number?

Ms. Taylor. Ms. Pelosi, for the last five years, there's been cuts in the treatment dollars going toward substance abuse, as the problems have been expanding. Treatment does pay. The California study indicated that, for every dollar invested

in treatment, there are seven dollars in benefits that are saved in health care costs, in traffic fatalities, and criminal justice costs. As we continue to make a large investment in criminal justice, we must think about a cost offset, and substance abuse treatment can do that. Two hundred million dollars may sound like a lot, but across the country, with the number of people that are on waiting lists for treatment, it doesn't go very far.

Ms. Pelosi. I appreciate that. Doctor, could you just briefly explain way the KDA grant, as opposed to a block grant, tends to be a more innovative and effective approach?

Ms. Taylor. The block grant goes to the States and allows the States to add infrastructure development and new programs, as well as to maintain their own. The knowledge development application allows the Federal Government to offer a rapid response to jurisdictions that are hit with emerging epidemics. For instance, in the Northeast corridor, the drug of choice is heroin, but in California, Ms. Pelosi, as you are aware, the drug of choice is methamphetamine, particularly affecting young people. Therefore, if the Federal Government was to have a uniform response across the country, some jurisdictions would not have the flexibility for either rapid mobilization of essential resources or target-specific mobilization, and the knowledge development application resources allow that.

Ms. Pelosi. Thank you very much, Dr. Taylor, for your testimony, for your answers, and for your leadership on this important issue.

Ms. Taylor. Thank you so much.

Ms. Pelosi. Thank you, Mr. Chairman.

Mr. Porter. Thank you, Ms. Pelosi. Thank you, Dr. Taylor.

[The prepared statement of Sushma Taylor follows:]

[Pages 562 - 570--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

GAIL H. CASSELL, AMERICAN SOCIETY FOR MICROBIOLOGY

Mr. Porter. I want to at this point apologize. We have nine witnesses remaining. We are at seven minutes of 12:00. Obviously, we're running very substantially behind. Partly, that's due to the fact that we've had several celebrity witnesses and have taken longer with them and have caused ourselves to come behind. I'm going to try to keep us--if we allocate just five minutes, we're going to run until 20 minutes of 1:00 as it is. So I'm going to try to keep us on our time targets as much as we possibly can for the remaining witnesses, with an apology that it certainly wasn't intended to squeeze your time, because your time is just as important as anyone else's, but we'll do it as quickly as we can.

Dr. Gail H. Cassell, past president of the American Society for Microbiology, Chair, Public and Scientific Affairs Board, and director of infectious diseases research at Lilly Research

Laboratories, Indianapolis, Indiana, testifying in behalf of the American Society of Microbiology. Dr. Cassell, welcome.

Ms. Cassell. I'd like to start out, Mr. Porter, by thanking you for your previous commitment to biomedical research and support for NIH, and to just say that this previous investment, as you probably are aware, has resulted in enormous benefit and improvement of human health, particularly in the area of infectious diseases. It has resulted most recently in technologies to allow us to completely sequence the entire genome of infectious agents. As a result of this, it's led to new targets for development of new antibiotics, new candidates for vaccines, as well as new diagnostics. As you will see in the remainder of the testimony, this becomes all important in today's world of infectious diseases.

Having said that, and also to point out that this investment, as you are also aware, not only has resulted in improvement of health, but also continues to improve and contribute to the economic prosperity of the country. Having said all this, however, the American Society for Microbiology as many congressional leaders, as well as individuals, believe that the Federal Government is not making a sufficient investment in biomedical research. We would like to see this increased. Therefore, we do support a doubling of investment in research, and along those lines, would support a 15 percent increase in the budget of NIH for this year.

We feel that we can best make the case for encouraging you to support this increase by using infectious diseases as an example. While I'd like to be very informal about this, in line with your desire to keep on time, I'll direct my comments to my written comments, but would be happy to answer any questions.

As you are well aware, each day headlines not only in the national news, but also international news describe new diseases that are rapidly arising worldwide and old diseases that are re-emerging as infectious agents evolve or spread, as changes occur in ecology, socioeconomic conditions, and population patterns.

Humans, through rapid world travel and unprecedented trade, can transport disease from one country to another today often in less than 24 hours. Infectious diseases not only are spread from human to human, animals to humans, but also, as you are aware very acutely, I'm sure, there is a tremendous threat from bioterrorism today. This, too, directly involves manipulation of infectious agents. So threats posed by infectious diseases not only to our well-being, but also to now national and world security are apparent.

What I would like to emphasize is something that you may not be aware of. Most people, when you tell them that infectious diseases are the leading cause of death worldwide, it is already known by them because most of these diseases occur in developing countries. What you may not be aware of is that infectious diseases, as of last year, became the third leading cause of death in the United States. Many people would immediately respond, ``Aha, HIV.'' I would point out to you that this increase in infectious diseases and death, however, are related to pneumonia in otherwise healthy individuals, as well as a significant increase in bloodstream infections.

In fact, what many people also may not be aware of in this

increased age of technology is that, since 1980, deaths due to infectious diseases in this country--again, not to HIV alone, but to the conditions that I've mentioned--have increased by almost 60 percent. These are data published last year by the Centers for Disease Control.

Antibiotics are now failing, as you probably have heard, to control common diseases such as bacterial pneumonia. In fact, last week a series began on CNN emphasizing the problems that we currently face with almicrobial resistance, and in fact this series will continue. Ninety percent of the strains of staphylococcus aureus, which is one of the most common disease-producing organisms in humans, are resistant to penicillin and other related antibiotics. The incidence of vancomycin-resistant strains of enterococcus, an organism that both you and I, and everyone in this room, normally carries in their intestinal tracts, but which is the most common cause of infections in hospitalized patients, the antibiotic resistance to this organism has increased twentyfold just since 1989.

As you are well aware, because of the publicity, food-borne diseases are responsible now for over 30 millionillnesses in the United States with over 9,000 deaths being due to infectious diseases, and this is only the tip of the iceberg with regard to food-borne disease.

Additional research is needed urgently to better understand the pathogenesis of these organisms, as well as hepatitis C, that we now know has a direct link to liver cancer.

We would say that the financial burdens of infectious diseases are staggering. Approximately $120 million or 15 percent of all health care expenditures are related directly to infectious diseases in this country.

I will pass by some of my other comments because of the interest of time. I will just say that, in conclusion, ASM realizes the difficulty of achieving the goal of doubling the NIH budget over the next five years under the current spending limits, but we certainly encourage you to significantly increase the resources, particularly in light of the problems that this country and the world face with regard to infectious diseases. We would urge you not only to take this into consideration with respect to NIH, but also the Centers for Disease Control, which also plays a very important role in this regard.

I appreciate the opportunity to tell you this directly.

Mr. Porter. Dr. Cassell, we definitely do hear you.

Ms. Cassell. Okay.

Mr. Porter. These are very serious concerns, and your testimony has highlighted them for us, and we appreciate your coming to testify today.

Ms. Cassell. Thank you.

[The prepared statement of Gail H. Cassell follows:]

[Pages 574 - 583--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

CHARLES N. QUIGLEY, CENTER FOR CIVIC EDUCATION

Mr. Porter. Charles N. Quigley, executive director, representing the Center for Civic Education. Mr. Quigley.

Mr. Quigley. Mr. Chairman, I appreciate the opportunity to testify here today on behalf of two programs in civil education supported by the U.S. Department of Education. These are a domestic program entitled, ``We the People,'' ``Citizen and the Constitution,'' and the ``Civitas,'' an international civic education program for former Soviet Bloc and Yugoslav nations conducted with the support of the USIA.

I've submitted written testimony. I'd like to highlight a few of the achievements of the program and say something about how they are complementary and interrelated.

The We the People domestic program is implemented throughout the United States with a volunteer network of about 500 coordinators at State and district level. In the international program, 15 States and the District of Columbia are now--the leadership is linked with eight former Soviet Bloc and Yugoslav nations in an exchange. For example, leaders in Alaska, the District of Columbia, Massachusetts, and New York are linked with their counterparts in Russia. Leaders in Arizona, California, and Nevada are linked with Bosnia and Herzegovina, Croatia, and Macedonia. Leaders in Indiana and Illinois are linked with Latvia and Lithuania.

As a result of these exchanges, programs developed for students in the United States are being picked up and used successfully with students in former Soviet Bloc and Yugoslav nations. For example, this text is used throughout the United States with millions of students at the secondary level in the domestic program. This is a Russian edition of this text, which was just printed by the Russian Teachers' Union. Fifty thousand copies are now being used with secondary students throughout Russia. This text is used in the United States as a basis of the National Academic Competition at the secondary school level. An exchange delegation from Hungary observed the program in Florida and have gone back and duplicated it in Hungary. There is now a nationwide academic competition based on this model Hungary. Last year, it was hosted by the President and Hungarian Parliament. The academic competition this May is expected to be even larger than the one last year.

The Center's new program at the middle school level, which involves students in grassroots politics in identifying public policy programs at the local level, action plans, participating in local community government, is now being used with the support of the National Conference of State Legislatures in 47 States in the United States.

This is a Czechs version being used in a pilot program in the Czechs Republic, a Slovak version being used in the Slovak Republic, a Croatian version being used in Croatia. There are also versions in Lithuanian and Latvian.

But perhaps the program we're most proud of is this version, which happens to be a Bosnian version, that is being used throughout the Federation of Bosnia and Herzegovina. There are now 1,500 teachers using this program in Bosnia, in the Federation. By the end of this year, we anticipate there will

be 50,000 students will have taken part in the program, which has been going for two years.

Last year, an historic event took place in Sarajevo in May in which classes from throughout the Federation came and participated in their first ever academic competition on democracy. We're pleased, and somewhat astounded, to be able to report that the Ministry in the Republic of Srpska has approved a program. It's being used now in the Republic of Srpska, and they intend to bring Serb students to the second competition in Sarajevo this May. That will be truly an historic event with students--Croat, Muslim, and Serbs all competing on fundamental principles of democracy.

The success of these programs has led our Russian colleagues and the Hungarians and Bosnians, and so forth, to suggest we hold an international competition on democracy, which we would love to do. We'll have to figure out some way to do that.

This program is a two-way street. We give and we get. These are lessons developed by teachers in Russia, Hungary, Poland, and the other nations I mentioned, which portraytheir experience in attempting to make the transition from totalitarian and authoritarian systems to constitutional democracies. These are now being distributed to 3,000 teachers in the United States to be used on a field test basis, and they have the potential to use them with as many as 200,000 students, American students, this spring semester to help American students understand what it's like to live in an authoritarian and totalitarian system, and perhaps develop a greater appreciation for their heritage.

Mr. Chairman, I'm pleased that the administration has requested a modest increase in the domestic program to enable us to expand Project Citizen at the middle school level. They've also requested continued funding of $5 million for the international program. Half of that goes for civics; half for economic education. The program has been so successful, the USIA has asked us to involve more States and more former Soviet Bloc countries in the program. So we're requesting a modest increase of $500,000 for each, civics and economics, a total of a million dollars, to help us implement the program in such countries as Ukraine, Georgia, Biolarus, and of course Albania, to help them overcome the devastating effects of the recent war with the United States. I couldn't resist the joke--excuse me.

I'm grateful for the opportunity to testify before you.

Mr. Porter. Mr. Quigley, I think you're doing great things, and you deserve our support and we're going to do the best we can to help you. That is exciting because that really makes a difference, and particularly when you're going people to people.

I was just in Cyprus trying to help them develop intercommunal projects that allow people who are on the side of the line that has divided their country for 24 years to have human contact with one another, just as a beginning----

Mr. Quigley. Yes.

Mr. Porter [continuing]. And if you can reach out to other people across the world the way you are doing in bringing the lessons of democracy and respect for each human being to them, I think that's absolutely wonderful.

Mr. Quigley. Thank you very much. I appreciate your support

in the past very much for the program.

Mr. Porter. Thank you for testifying.

Mr. Quigley. Incidentally, the Bosnian Minister of Education will be here in a few weeks, and I hope that you'll have an opportunity to meet him.

Mr. Porter. All right. I look forward to it.

[The prepared statement of Charles N. Quigley follows:]

[Pages 587 - 597--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

STANLEY O. IKENBERRY, AMERICAN COUNCIL ON EDUCATION

Mr. Porter. Stanley O. Ikenberry, president, American Council on Education, testifying in behalf of the Council. Stan, it's wonderful to see you.

Mr. Ikenberry. Thank you, Mr. Chairman.

Mr. Porter. Former president of the University of Illinois, one of our premiere and large public universities in our country, and we are old friends. So, Stan, why don't you proceed in any way you like.

Mr. Ikenberry. Well, thank you, Mr. Chairman. It's a real pleasure to be back here and, very frankly, a privilege. As I think you and I discussed at the close of the last session, the leadership that you and members of this committee have given to higher education funding, both for students, to open access, and to biomedical research has just been absolutely crucial, and it's widely recognized, certainly within the academic community, and I'm sure beyond that. If I do nothing else today, I want to thank you and members of the committee for the high priority that you've accorded higher education funding, and particularly student aid funding and biomedical research funding. It's open access; it's provided opportunity; it's provided choices and options to students that otherwise would not have been there, and overall, it's helped raise the quality of the academic enterprise and higher education in this country.

It's sometimes said that American higher education is the best in the world. Whatever our status may be, we need to get even better, if one thinks about the changes that are taking place in our society and the implications not just for individuals, but for the quality of life in our society and the economy. I thank you for the priority and the leadership that you've given this issue.

I know that time is limited, so let me just comment quickly on the linkages between access to higher education controlling college costs and the importance of the Pell Grant and other Federal student aid programs. Family circumstance, family wealth, continues to be a very significant factor in terms of defining whether an individual in this country will or will not have access to college. For those students in the highest income levels, the highest family income levels, for example,

they are more than 50 percent more likely, half again as likely to go on to college in contrast to the students at the lowest income level.

Last year, you made huge strides by increasing the minimum Pell Grant--or the maximum Pell Grant award by $300 to a $3,000 maximum. In addition, the innovative tax program that provides incentives and opportunities for middle-income families I think will have a tremendous impact. We still have a tremendous way to go. If one were to restore the Pell Grant maximum award to 1978 levels in terms of purchasing power, it would require about a 35 percent increase or morethan $1,000 increase. In our wildest dreams, we're not likely to do that this year, maybe this year or next year, but we need to continue to press to make progress on that front to close the gap.

The point, I think, it too often missed of the linkage, however, between strong student aid programs and the ability to control college costs. The campus student financial aid budget has been the most significant cost-increase driver on many college campuses, particularly private and independent institutions that need to provide access to students from middle-and low-income families.

Those tuition increases now have been headed down--the rate of increase has been declining for the last three or four years. Last year it was the lowest in 25 years. The National Commission on College Costs, just this past week, issued its report. I think that will be the No. 1 agenda on most college campuses across this country. Every president in the country shares this concern. But, I think, while we pursue that agenda at the campus level, it's important to note that a strong Federal student aid program, particularly a strong Pell Grant program, is very important to containing college costs.

One word also on the importance of campus-based programs: It's on the campus that student aid packages are actually put together, and it's a struggle for institutions, for students, and for families. The key is flexibility, but the Perkins needs-based campus student aid loan program is a terrific example of one program that's very important to campuses to be able to put together that tailormade package for individual students, as is, for example, the SEOG program and other campus-based programs. I simply wanted to stress the importance that we attach to that flexibility.

One final point: Mr. Chairman, you have received a great deal of testimony this morning, inspiring testimony, on the importance of biomedical research investment, and you, yourself, have demonstrated a tremendous interest in that area.

I wanted to return to an issue that's a bit of concern to you and to all of us, and that is the indirect cost recovery rate. I was pleased to read an article in The Chronicle for Higher Education and Beta on the top 100 research universities and the history of indirect cost rates from 1991 to 1997. The fact is that we've made some very significant progress on that front. A clear majority of these 100 institutions, 56 of the 100 institutions, had either reduced the indirect cost recovery rate or it had remained flat. The range of rates between the highest and the lowest had narrowed very significantly, and in the top 15 campuses with the highest indirect cost recovery rates, 14 out of the 15 had declined over that period. I think

we are making some significant progress on this issue as a result of improved accounting programs, stronger Federal oversight, and a higher priority on the agenda of college presidents themselves. I believe this will provide us a good foundation for the kinds of strengthening that you and others want to bring about in the biomedical research programs.

We know the budget pressures you face, and again, are grateful for the priority that you assign these issues because a strong Pell Grant program and other Federal student aid programs really is crucial not just to our campuses, but, more importantly, to students and families and the future of the country.

Again, I thank you, Mr. Chairman, for the ability to come before you again.

Mr. Porter. Thank you, Dr. Ikenberry. Stan, I have to say that we'll do our very best. I think you probably heard my two sermonettes earlier today about budget. Those are very important points.

Mr. Ikenberry. We understand that completely.

Mr. Porter. I know you know them. So we appreciate very much your coming to testify.

Mr. Ikenberry. Any way we could work with you to help you, we want to do that. Thank you.

Mr. Porter. Thank you.

[The prepared statement of Stanley Ikenberry follows:]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 601 - 606--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

ANN L. JENICH, NATIONAL ASSOCIATION OF ANOREXIA NERVOSA AND ASSOCIATED DISORDERS

Mr. Porter. Ann Jenich, ANAD, director of special projects and State of Illinois Board member, testifying in behalf of the National Association of Anorexia Nervosa and Associated Disorders. Ms. Jenich? Did I pronounce your name right?

Ms. Jenich. You're the first person to pronounce my name right in about five years.

[Laughter.]

My name is Ann Jenich. I'm director of legislative affairs for the National Association of Anorexia Nervosa and Associated Disorders. Our acronym is ANAD. On behalf of ANAD, I'm deeply grateful to Congressman Porter and the members of the subcommittee for this opportunity to appear and give testimony on behalf of the estimated 8 million women and men in this country who are suffering from often life-threatening eating disorders.

I also want to take this time to personally thank

Congresswoman Lowey for her efforts on behalf of eating disorders by securing $1 million for the implementation of an eating disorders education and information hotline. It's an important first step. Educating people to the dangers and to the widespread nature of this illness is important, but education alone is not enough.

Founded in 1976, ANAD is our Nation's oldest nonprofit organization dedicated to alleviating the problems of eating disorders. ANAD early detection, education, and prevention programs provide models for low-cost outreach services that benefit hundreds of thousands of people over the past 20 years.

As a woman who has survived an eating disorder, it is also my privilege to speak out forcefully today about the dangers eating disorders pose to the physical and mental well-being of an epidemic number of America's youth, and in knowing this, on the importance of expanding programs, services, and research, particularly applied research, aimed at preventing another generation of youth from developing eating disorders.

The issue--and I'm sure you all know this--of eating disorders cuts to the very heart of the collective power, self-esteem, and life success of a generation of young people. This is a major public health problem, one that seriously impairs and often endangers the lives of a vast majority of people who develop these disorders.

Eating disorders as a phenomenon are culturally-embedded in the experience of American young adulthood, and while these problems are especially acute for our Nation's girls, we know they are shared with a growing number of boys. What is the matter? Why do so many young women reject their bodies? Why is it that for 80 percent of American young women being female means feeling too fat? And I know I justspent a weekend at the University of Illinois working with the Panhellenic Institute, and I will tell you everybody had a story to tell.

What are the consequences to our Nation's children of adopting such deeply-distorted body images? We also know that people's body images are shaped at very young ages, and teachers are telling us, our organization, that girls as young as 5 and 6 are overly concerned with their weight.

The National Institute of Mental Health reports that 1 out of 10 people with anorexia nervosa will die. A staggering 1 in 4 college-age girls will struggle with some form of an eating disorder. It is logical to assume that a potential consequence of the negative relationship many of America's children develop with their bodies is in part associated with the dramatic rise in eating disorders. In fact, Dr. Harold Goldstein, Director of the National Institute of Mental Health, reports that the incidence of anorexia and bulemia has doubled over the last decade. We are also seeing in our organization second-generation children from mothers who have anorexia or bulemia appearing over our hotline.

Eating disorder specialists, educators, and researchers are corroborating those findings. We are also listening to teachers during the conferences and the workshops that we host--the same thing.

Given the epidemic of disordered thinking, graphically illustrated in these statistics, and the undenial influence of the media on the developing self-concepts of America's

children, it is no wonder that there is a cultural mindset in place by the time they reach adolescence that places millions of our children at risk.

Death and disability rates from eating disorders are among the highest of all mental illnesses. Yet, both in number of victims and cost of treatment, eating disorders are major illnesses in our country which do not now, and have not ever, received adequate understanding or support.

For example, allocations to combat alcohol, drugs, or schizophrenia and effective disorders are each funded at exponentially higher rates than the amounts given to eating disorders. Yet, for illnesses like eating disorders, there is also inadequate information available to the general public about these disorders, and we are grateful again, as I said, for the hotline.

Our organization just completed a landmark survey of 50 States and we conducted a survey to assess the types of eating disorders, programs, and services available to American citizens. Preliminary survey results reveal a widespread deficit in educational information available to all Americans. In fact, at the grade school level, there was very little available information to teachers about just the basic etiology of eating disorders, let alone prevention. Given the pervasive nature of these disorders, in our minds that's shocking.

Knowing this, coupled with the fact that there's an only estimated 50 percent cure rate for those suffering from chronic eating disorders, we believe there is a dire need for Federal funds sufficient to establish a national comprehensive prevention program to protect our citizens from these illnesses.

While evidence of the need for primary educational programs is indisputable, it is not enough. It is critical, if we hope to reduce the prevalence of these illnesses, to also provide long-term opportunities for our children and youth to examine and challenge the attitudes and behaviors that lead to eating disorders.

Programs and prevention must go beyond addressing problematic and symptomatic behavior to teaching resistance to cultural values and attitudes that diminish a young person's self-esteem. To be truly effective, prevention programs should focus on teaching children the skills necessary to cope with the emotional complexities of life in a positive, life-affirming way. We believe this can be most effectively achieved through school-based programs and support groups.

I want to make a personal comment here. There's very little emphasis on this at the research level and very little being done out there, but at the University of Arizona there has been a study that is just completed, and the results are very, very positive. It was a longitudinal study. It was a school-based study, and we need to do more studies and fund more studies of that nature.

For this reason, we urge Congress to allocate $10 million for use in developing comprehensive education and prevention of eating disorders through early detection and educational wellness programs for all of America's school-age children. As a recognized leader in this field, we believe our organization could provide a model for this service.

We also believe, and we know, that eating disorders are multi-causal. For this reason, we ask Congress to increase current funding for the research necessary to further investigate the causes of these disorders, and not just funding for drug studies. This funding is essential if we are to develop truly inoculative prevention programs.

We ask Members of Congress to do all that they can today to enact legislation assuring that the problems and issues of people suffering from eating disorders are adequately addressed, so that we can look forward in the future to eradicating these deadly illnesses that so adversely impact our youth in this country.

Thank you.

Mr. Porter. Ms. Jenich, we thank you for coming to testify. The association is in Highland Park, Illinois, in the heart of my district. Are you a constituent?

Ms. Jenich. I am.

Mr. Porter. Well, we're delighted that you could come.

Ms. Jenich. But I am a Packer fan, I want to tell you.

Mr. Porter. A Packer fan?

Ms. Jenich. Absolutely.

Mr. Porter. Well, the Bears don't leave you much choice these days, though.

Ms. Jenich. It's been a long winter.

Mr. Porter. I would say so.

I'm dismayed at the degree to which you say we are falling short in this area. Congressman Lowey has been a very strong advocate, as you mentioned in your testimony. I have great concern about these diseases, and we simply are going to have to do better.

Ms. Jenich. Okay. I'd also like to say one more thing. We are meeting this week with the legislative assistants for the women who are on the caucus, the Congressional Caucus, and one of the things we are asking the caucus to do is to initiate a letter to President Clinton asking him to develop a task force to take a look at the issue of eating disorders in this country, and also the bigger issue of body image distortion that many women seem to suffer from.

Mr. Porter. Thank you so much for coming to testify.

[The prepared statement of Ann Jenich follows:]

[Pages 611 - 618--The official Committee record contains additional material here.]

WITNESSES

RONALD KRAMIS, FIBROMYALGIA NETWORK

Mr. Porter. Ronald Kramis, Ph.D. neurophysiologist, testifying in behalf of the Fibromyalgia Network.

Mr. Kramis. Yes.

Mr. Porter. Dr. Kramis.

Mr. Kramis. Thank you, Mr. Chairman. In light of your sermonette, I would like to emphasize that your capability to direct the attention of NIH to the subject of my presentation is extremely important. There's a huge fund of information in

the basic neurosciences that is yet not being applied to fibromyalgia. It's important that the attention of NIH, as well as some funding, be directed toward this disease.

Fibromyalgia is a persistently painful disease which costs this Nation $20 billion in health care and socioeconomic costs. I want to talk to you particularly about the unremitting life of pain that is associated with fibromyalgia. This is a pain which destroys careers and disrupts. This is a pain for which there is no truly effective treatment. This pain is endured day after day, year after year, by over 5 million Americans. Right now, because of progress in the basic neurosciences and the clinical neurosciences, you and NIH have a tremendous opportunity to help these 5 million Americans. You can do so by focusing attention on this disease, both the attention of NIH and the attention of the scientific community.

The pain of fibromyalgia is a deep and sometimes agonizing muscular-skeletal pain that is perceived to occur throughout the body. Just as with many other chronically-painful conditions, such as severe low back pain, fibromyalgia pain occurs in the absence of any apparent injury or disease in the tissues that are felt to be painful. This often raises questions of credibility for individuals suffering from fibromyalgia and for the disease itself, particularly within the health care insurance industry.

Let me assure you as a neuroscientist who has been studying the biological mechanisms of pain for many years, even severe and persistent pain can occur without pathology being present in the tissues which are felt to be painful. Many of the biological mechanisms by which this can occur are already understood, some of them even at the molecular level. It's a tragedy for individuals who suffer the unremitting symptoms of fibromyalgia and other chronically-painful conditions that so few clinicians, scientists, and health care administrators understand the biological mechanisms of pathological pain.

I'd like to encourage you, now or at some other time, to try a little experiment which will help you understand how easily muscular-skeletal pain can occur in the absence of tissue damage. Just reach across your chest with your thumbs and all four fingers and squeeze the large muscle that runs from the back of your neck to your shoulder. A firm squeeze but one that is certainly not tissue-damaging will become uncomfortable. If you squeeze a bit harder, then hold that squeeze for a minute or two, or even a bit longer, if you can, you will have some understanding of the pain that fibromyalgic patients go through day after day, year after year.

Two neurologically important substances, both known to be involved in the generation of persistent pain, have recently been shown to be present in pathologically high concentrations in the central nervous system of individuals with fibromyalgia. This indicates that fibromyalgia is probably a central nervous system disorder rather than a muscular-skeletal disorder, as originally thought.

In spite of these recent discoveries, there remains no effective treatment for fibromyalgia. Even narcotic analgesics do not provide effective remedies for fibromyalgia pain.

Fibromyalgia interferes with all aspects of a person's life. There are many symptoms associated with the disease other

than pain itself. Even the normal activities of everyday life exacerbate the pain of fibromyalgia and produce abnormally intense fatigue.

Fibromyalgia is severely disabling. Twenty-six percent of patients recently surveyed were receiving disability payments. Fibromyalgia frequently evolves from a prior, more restricted, more localized painful condition. In two recent studies, 25 to 50 percent of patients with chronic, localized, low back pain eventually develop the total body pain of fibromyalgia.

Fibromyalgia occurs eight to ten times more frequently in women than in men, and is to some extent familiar. This suggests a gender-link genetic component to disease.

Now despite the $20 billion socioeconomic and health care burden of fibromyalgia, funding for fibromyalgia research is practically unavailable. On behalf of the 5 million American men and women who endure fibromyalgia and on behalf of Fibromyalgia Network, the largest self-help organization, I urge this committee, through NIH, to focus the attention of the scientific community on the fibromyalgia syndrome. As the result of recent discoveries in the neurosciences, this is the right time to fund fibromyalgia research.

Thank you very much.

Mr. Porter. Dr. Kramis, thank you very much for your testimony.

If I understood you correctly, this disease---has anybody looked into the mental aspects of the disease, or is it clear it's physiological.

Mr. Kramis. There right now is a considerable discussion within the scientific and clinical community concerning this. In any chronically-painful condition you are going todevelop some psychologically-associated conditions, but it's very clear that there are physiological mechanisms here which are known from the basic sciences to be related to persistent pain that are occurring in these individuals, and there is, I think, a really unfortunate tendency right now because the medical community does not have good means to treat this disease and does not understand. To say the easy answer--it's a mental problem; we can't treat it as a physiological problem; let's do a cost-containment study; let's get rid of these people, not treatment them--these people have a real disease; it's not going to go away. We are going to continue impacting the socioeconomic system, and cost containment alone is not the answer. We've got to find the cause.

Mr. Porter. The reason, I asked is we had testimony--we had a special hearing on the role of the mind in health and healing, and there was testimony that a great deal--and you mentioned back pain, related back pain, in respect that a great deal of the back pain, which is a huge economic burden in our society--practically 80 percent of the American people experience it sometime, severe back pain--that that may be related to stress.

That's the reason I asked whether this pain might also be related to stress, but you're saying that there's obviously clear physiological causes for it?

Mr. Kramis. There are clear physiological causes, and with low back pain, 95 percent of the cost you're talking about occurs as the result of 5 percent of the individuals with back pain, and those are individuals with what's called idiopathic low back pain for which there is not an obvious physical cause.

But if you look at the neurosciences, basic information in the neurosciences, there are mechanisms that just are not getting through to the clinical community, that can, in fact, give good reason why pain can occur in the absence of obvious physical pathology. It's a neurological mechanism. You don't generate pain in the tissues that feel painful; you generate pain in the central nervous system. And if there is disorder in the central nervous system--and, in fact, a common process called central sensitization--you will get abnormal levels of pain, and it doesn't require that you have a severe physical, pathological condition in the peripheral tissue in order that you feel extreme pain, as if it were occurring in those tissues.

Mr. Porter. Dr. Kramis, thank you very much for your testimony.

[The prepared statement of Ronald C. Kramis follows:]

[Pages 622 - 631--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

HEATHER FRASER, CYSTIC FIBROSIS FOUNDATION

Mr. Porter. Heather Fraser, consumer and legislative affairs coordinator for the Cystic Fibrosis Foundation. Ms. Fraser.

Ms. Fraser. On behalf of the 30,000 children and young adults with cystic fibrosis in this country, the Cystic Fibrosis Foundation is pleased to submit public witness testimony to support Fiscal Year 1999 appropriations for the National Institutes of Health. The Foundation applauds the subcommittee for the CF-specific language included in the appropriations bill last year. This vote of confidence in the NIH served to make the future for me and many others with CF much brighter.

This year you have been hearing testimony punctuating the need for increased Federal funding for many entities, including medical research. It's my hope, however, that one day there's not going to be a need for extensive deliberation--not because an infinite pool of resources has suddenly become available, but because a portion of that need has been eliminated.

The Cystic Fibrosis Foundation urges the House of Representatives to concur with the President's recommendation to double the funding for the NIH over the next five years, and as a downpayment on this commitment, provide an increase of at least 15 percent in 1999. We request your continued support of the full spectrum of research--basic, clinical, and translational--sponsored by the NIDDK and the NHLBI.

The resource capacity of these two institutes is of paramount importance to propel the frontiers of CF research into the millennium. We believe this funding level is justifiable and appropriate allocation, given the clear and pressing research opportunities that exist.

Current biomedical research policy only enables funding of

two out of every ten approved research grants. This is unconscionable, and one cannot help but wonder what progress could emerge and how many lives could be saved if all of these meritorious grants were funded.

Support to general clinical research centers must also be increased. These 74 NIH centers are specifically equipped to provide support to clinically-trained investigators to examine disease conditions and to access new therapies. With the advent of managed care and the increasing constraints that academic medical centers are placed under, more and more ancillary costs for clinical trials are being placed on the shoulders of the GCRCs. These centers are pivotal to the identification of new therapies to treat and eventually cure cystic fibrosis and other life-threatening illnesses.

Further, the CF Foundation asks this subcommittee to direct the NIDDK, NHLBI, and the National Center for Research Resources to develop key mechanisms to ensure rapid translation--and I emphasize ``rapid''--of basic researchinto new therapeutic interventions. Creative development of an institutional infrastructure similar to that already in existence to support basic research in teaching institutions should be created to support and monitor ongoing clinical trial investigations.

The NIH has an incredible track record in developing basic research and understanding cellular processes. However, it is unbelievably naive to think the pharmaceutical and biotech industries are prepared or in a position to lead the effort to take this knowledge and follow the clinical evaluation. Unless there is a permanent mechanism in place, drug development opportunities, along with many, many lives, are going to be lost unnecessarily.

Clinical research training opportunities must also be expanded. Well-trained clinical investigators are vital to further progress made in the research lab and to translate that progress to patients. Never before has the need been more urgent and the number of candidates so small. Additional initiatives in post-doctoral training, support for new and young investigators, and programs to facilitate the mentoring of these individuals are pressing priorities.

In closing, the National Institutes of Health and the Cystic Fibrosis Foundation continue to work together to provide for leadership in this country that is unparalleled. As a foundation, we understand current funding constraints and that Federal programs, regardless of their merit, have been placed in competitive positions. However, I can tell you as a patient at the end of the day when I return home exhausted, in part due to work, but more worn out as a result of dealing with the daily rigors that are the unwelcome hallmark of this illness, that cavalier acceptance is just not justified.

Sadly, there will be casualties at the close of this debate. Nevertheless, we must work together and ensure that the human cost is kept to a minimum. On behalf of the CF Foundation, I again urge this Congress, in particular, this committee, to seriously consider the President's recommendation to double the NIH appropriations over the next five years, and in particular, provide a 15 percent increase in funding for 1999.

Thank you for allowing me to testify today.

Mr. Porter. I'm inclined to say, tell us how you really feel, Ms. Fraser--[laughter]--but, no, I think your testimony was very strong. The President, unfortunately, has proposed to double the funding over the next ten years, not the next five years. His rate of increase is good. I'm encouraged by it, but it is not what we have suggested. It has raised his level of commitment dramatically to--I think the increase for this year would be about .2 percent for science research, but we think that 15 percent is a much nicer figure. But it is encouraging.

I have to say that the funding of meritorious grants is low. The reason it's low, though, isn't that we aren't putting more resources into research. It's that there is so much more meritorious science out there to fund, and what we need to do is to ramp-up our funding to capture more of that earlier, and help in diseases like cystic fibrosis, where the chances for breakthroughs are good. What it tells us is that the historical level of about 3 percent in real terms per year that NIH has experienced over its whole 50-year lifetime is really not enough, considering how fast science has advanced in recent years, and we need to increase that real rate of increase much faster. So that's why we're all raising our sights, and in that process the President is raising his sights, too, and I think that's very positive, to try to move him along even a little more.

Thank you for your good testimony.

[The prepared statement of Heather Fraser follows:]

[Pages 635 - 639--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

PETER REUTER, PH.D., COLLEGE ON PROBLEMS OF DRUG DEPENDENCE

Mr. Porter. Dr. Peter Reuter, Chair, Public Policy Committee, representing the College on Problems in Drug Dependence. Dr. Reuter--I've got to put my glasses on here. Dr. Reuter.

Mr. Reuter. It rarely is pronounced correctly, even by reporters.

Mr. Porter. Is it----

Mr. Reuter. It is Reuter. Thank you.

Mr. Porter. I read the ``e'' as an ``s,'' I'm sorry.

Mr. Reuter. I'm pleased to appear before you today on behalf of the College on Drug Dependence, the oldest society for research on drug dependence and drug abuse, to urge your continued support from the National Institute on Drug Abuse and the Substance Abuse and Mental Health Administration. This committee has provided great backing in recent years for the NIDA budget. An almost unparalleled 7.6 percent increase--we pay attention to the decimal points quite closely--given in Fiscal Year 1998 is enormously appreciated by the college, and we urge that you provide a substantial increase in the funding base this year.

As both the President and Senator Lott stressed in their speeches on Tuesday night, the continued high levels of adolescent drug use and smoking represent major public health problems for the Nation. The administration has drafted a plan for reducing drug use by 50 percent in the next tenyears. Some of your colleagues believe that this is insufficiently ambitious and propose that the same goals should be achieved in five years. In either case, success is critical dependent on the continued flow of research breakthroughs that can only be secured by NIDA-based new technologies in SAMHSA from the training and implementation programs.

Let me illustrate the problem presented even by the administration's more modest goals for adolescent drug use. In 1996, according to the Monitoring the Future Survey, 24.6 percent of high school seniors reportedly used an illicit drug in the prior 30 days. In the 23 years of monitoring the future, that rate has never been lower than 14.4 percent, which was in 1992, and that level was sustained precisely for one year and rose to over 18 percent the following year. Yet, the administration's target is to reach and sustain a level of 12.3 percent ten years from now, an historically unprecedented low rate.

The challenge here is simply in relative ignorance about what determines drug use amongst adolescents. The dramatic cycle in adolescent drug use over the past 20 years, the sharp increase in the late 1970s followed by a very prolonged and substantial decline throughout the 1980s, and then a sudden rebound in 1992, are known to be related to adolescent attitudes toward risk of drug-taking. What we don't know is what led to the changes in attitude that have driven the increases in drug uses recently. The most profound theory accounting for the upturn after 1992 is the two-word phrase: generational forgetting, which is hardly the basis for serious research or policy.

Thus, we do not know how to reliably affect attitudes through prevention activities. That requires, first, careful development of model prevention programs based on the strong theoretical understanding of what drives adolescent behavior, and then these programs must be tested on a large scale to ascertain how they can effectively be implemented across the many school districts and local family service agencies in the country. So many model programs fail in the implementation, which needs to be studied itself.

Absent substantial improvements in our knowledge base, the Nation's ability to achieve historically low adolescent drug use is very questionable. The same is true for smoking initiation rates. Your support for NIDA is vital since current prevention and treatment programs are simply not powerful enough to assure that, even with adequate funding of those programs, they can achieve the goals of reducing adolescent smoking rates by 60 percent in ten years, which is the goal that most Members of Congress and advocates have accepted or induce most current smokers to quit.

The combination of large-scale epidemiological studies in laboratories on the addictiveness of nicotine have been critical in creating a public awareness of the dangers of smoking, particularly of initiation, and having to force the tobacco companies to accept the responsibility for public

health disaster of the first order.

NIDA funding provided the initial research leading to the development of nicotine patches, and NIDA and other NIH institutes have improved the efficacy of gums and patches as replacement therapies. These advances have enabled large numbers to give up tobacco smoke, smoking.

But given the time it takes to test and implement new programs, the 10-year goals require substantial immediate investments in research. Thank you for providing this opportunity to testify.

Mr. Porter. Dr. Reuter, I suggest--and this is not scientifically verifiable, either--that perhaps the reason for the rise in the use of drugs and tobacco relates to what our young people see on television, what our celebrities, sports figures, and public figures stand for in their minds, and role models that are positive and lead to positive behavior I think are terribly important for young people. Often we see only bad evidence of bad character, and maybe that is what is affecting these kinds of behaviors.

Mr. Reuter. I'm sure you're right----

Mr. Porter. And I'm not referring to anything current; I'm simply saying this is often what we see, and I think it sends all the wrong signals. It's the nature of our media. You never see the good things; you only see the bad.

Mr. Reuter. Bad news is much more interesting----

Mr. Porter. Yes.

Mr. Reuter [continuing]. As the last week has suggested.

Mr. Porter. I'm afraid so. Thank you for your testimony.

[The prepared statement of Peter Reuter follows:]

[Pages 642 - 649--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

PHYLLIS GREENBERGER, SOCIETY FOR THE ADVANCEMENT OF WOMEN'S HEALTH RESEARCH

Mr. Porter. Phyllis Greenberger, executive director of the Society for the Advancement of Women's Health Research, testifying in behalf of the Society. It's nice to see you.

Ms. Greenberger. Well, I was going to say ``good morning,'' but it's afternoon.

Mr. Porter. Yes, I'm sorry, we are really running so late here.

Ms. Greenberger. Good afternoon to you, Mr. Chairman. I thank you very much for the opportunity to testify.

As noted, I'm the executive director of the Society for the Advancement of Women's Health Research, and we're the only national organization committed to improving women's health through research, and I'm here today to voice our support for increased funding for a variety of women's health research programs.

I'd like to begin by saying that we support, needless to

say, many of the previous statements regarding the increases in the funding for the National Institutes of Health. I'm sure it hasn't gone unnoticed that many of the conditions that were mentioned to you this morning--from Interstitial Cystitis, fibromyalgia--disproportionately affect women, and so, obviously, this is an area that we're most concerned about and request your support.

And what we support, obviously, are these increases across the Institute for these conditions. You will,obviously, be hearing from many more of these in the next few days, and we want to talk about another area that we feel that really includes all of them, and so that we are not separating out women's diseases from men's diseases or one institute from another.

You may be aware that women's health research is moving into a new era, and that is, it's branching out to look at gender-based differences at the cellular and the molecular level. Researchers are discovering the roles hormones play in the development of various organs and the etiology of diseases, and understanding these gender differences and their implications for clinical care will likely find results beneficial to both genders.

There have been several recent examples of gender differences. I'm sure your aware of the differences in cardiology. We all recognize differences in neurology and immunology, and we are just realizing that these differences exist. As I know you know, for many years we weren't looking at these differences between genders, and we weren't including women in clinical trials systematically, and so these differences went unnoted. But now that we know that they do exist, we need to encourage research in these areas and understand the implications.

The Office of Research on Women's Health provides a unique focus at NIH in accord with its mandate to, I quote, ``develop an integrated strategy for increased research into diseases, disorders, and conditions that are unique to, more prevalent among, or more serious in women, and for which there are different risk factors of interventions for women than for men.''

The office also provides a pivotal point for communications among the institutes and centers for proactively developing multiple disciplinary research opportunities for women's health research, as well as ensuring the inclusion of women and minorities in clinical trials across the institutes, and we commend the NIH on its extraordinary recent discoveries in genetics and cancers predominantly affecting women. While there are numerous conditions that need attention--and, as I said, will be addressed before this committee--I would like to just emphasize one which actually was mentioned by Judy DeSarno earlier, but I'd be remiss if I didn't.

As a member of the Presidential Advisory Committee on HIV/AIDS, we urge the NIH to expand its research portfolio in the area of microbicides to help prevent the spread of HIV infection and other sexually-transmitted diseases. There is a great need to develop contraceptives and microbicides that are unnoticeable, fast-acting, inexpensive, safe, and effective.

To accommodate the health needs of the population for 1999, we recommend overall increases of 15 percent for the women's

health budget and the NIH as a whole, tying the Office of Research, Women's Health, to the overall NIH addition in funding.

In addition to the NIH, AHCPR actually has been mentioned, but we'd like to mention that for a moment again, but also a couple of other agencies that have not been mentioned. I'm sure you know that in the Office of Women's Health, recently, the last two years, there has been funding for centers of excellence within the Public Health Service, and the Society would like to recommend doubling the funding for that.

There is a great need to leverage resources within academic health and medical institutions, and this program provides the development of a multidisciplinary research agenda on women's health issues and comprehensive and integrated health care services for the special needs of women. It also provides public and health professional education and training.

The Agency for Health Care Policy and Research, as I stated, has been mentioned previously by Dr. Lurie and Dr. Hobbs, but we would like to emphasize that as well. Despite improvements, women still lag behind men in quality of care and access to health services. For them, in particular, the work of AHCPR is vital.

For example, the agency is supporting the study that looks at the widely-reported differences in medical treatments--specifically, cardiac procedures--for women and men, and patients of different races. To continue to implement this agenda, the Society would like to recommend a 20 percent increase in funding for AHCPR.

I'm going to quickly run through this. I'd like to mention an area that has only been mentioned briefly, and that is the Center for Disease Control and Prevention, Office of Women's Health. This agency ensures that women's health and prevention needs are addressed, and it's committed to projects that address gaps in CDC programs and differences among subpopulations of women.

Again, we recommend a 15 percent increase in CDC funding, and I don't have to tell you--and I have statistics here which you already know--an ounce of prevention is worth a $1,000 in cure. So we all know that we need prevention, and we need to strengthen the CDC, and particularly, obviously, as a women's health research organization, we are concerned about the implications for prevention in the area of women's health research.

I appreciate the opportunity to testify. Obviously, my complete remarks will be, hopefully, entered into the record.

Mr. Porter. Yes, they will.

Ms. Greenberger, Ms. Lowey and Ms. Pelosi have beenwonderful advocates for women's health research, and I know that when we go to mark up the bill, they will be right there along with others on the subcommittee, because this is a subject of great concern to us.

Ms. Greenberger. We appreciate that, and we very well know Congresswomen Lowey's and Pelosi's and DeLauro's support as well as yours for these areas, and we very much appreciate it.

Mr. Porter. Thank you very much for testifying.

Mrs. Lowey. Mr. Chairman, just briefly----

Mr. Porter. Ms. Lowey.

Mrs. Lowey. I just want to take the opportunity, actually, to thank our chairman. The chairman has been probably the strongest advocate for funding for the National Institutes of Health, and obviously, as we are making these difficult choices, we should all continue to work as hard as we can to increase the investment in the National Institutes of Health, thereby allowing greater investment in so many of the areas where we care passionately about, and that you testified about.

I want to thank you and the Society for Women's Health for your strong advocacy, because you have been very vital in this effort, and in putting together a board of first-class scientists, you have been very helpful to us in helping us establish our priorities. So I want to thank you, Phyllis, and the Society for your leadership in this critical area.

I thank you, Mr. Chairman.

Mr. Porter. I did not mean to leave out Ms. DeLauro. We missed her for two years, and then she's definitely back.

Thank you so much.

Ms. Greenberger. Thank you very much.

[The prepared statement of Phyllis Greenberger follows:]

[Pages 653 - 659--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

DAVID BECK, CHAIR, ASSOCIATION OF INDEPENDENT RESEARCH INSTITUTES

Mr. Porter. Last, but certainly not least, Dr. David Beck, Chair, Government Relations Committee, and immediate past president, Association of Independent Research Institutes, and president of the Coriell Institute for Medical Research in Camden, New Jersey, testifying in behalf of the Association of Independent Research Institutes. Dr. Beck.

Mr. Beck. Thank you, Mr. Chairman. On behalf of the Association of Independent Research Institutes, abbreviated AIRI, I thank you for the opportunity to testify before you today and to help build the record that will enable you to carry yours and the committee's passion on health research to the full Congress.

AIRI is an association of not-for-profit research institutes that conduct basic and clinical research in the biomedical and behavioral sciences. Our institutes receive about 10 percent of all of the NIH extramural funding, as well as extensive funding from other Federal and private agencies, foundations, and corporations. AIRI are distinct from other organizations involved in biomedical research in that our primary mission is research. I am here not only as a participant in the biomedical research enterprise, but also because I believe passionately the potential of the work that we are doing has to provide enormous benefits for the Nation's health and for its economy.

Mr. Chairman, over the past few years, you and your subcommittee have stood firm in your support of NIH and its

mission, and your faith has been rewarded by the extraordinary progress in understanding the processes of life that you have heard about so many times before you today and at other times. We ask you to demonstrate your support once again for the work of NIH by providing a 15 percent increase in funding for the Fiscal Year 1999, as called for by the Ad Hoc Group for Medical Research Funding. We at AIRI support the Ad Hoc Group's position that sustained funding, sustained growth in funding, for the NIH is needed to capitalize on past scientific achievements, address present medical needs, and anticipate future health challenges. This sustained growth that we are seeking, beginning with a 15 percent increase and culminating with a doubling of the NIH budget, is needed not merely to accelerate the pace of research, but the fundamental way science is being done is being revolutionized. Science will require new investment in new technologies, new infrastructure, and personnel with new sets of skills. This investment is necessary to ensure that the research community can take full advantage of these new approaches to discovery.

AIRI members know firsthand what has been accomplished with NIH research, and we know how much more can be done with additional NIH funding. I would like to cite for you just afew examples of successes achieved at AIRI institutions with NIH support over the last year.

At the Whitehead Institute in Cambridge, Massachusetts, Dr. Peter Kim produced the first picture of a protein that enables the AIDS virus to invade human cells, work that has immediate implications for new drug design.

At the Oklahoma Medical Research Foundation in Oklahoma City, researchers have been able to establish a powerful association between the Epstein-Barr virus and lupus, a serious autoimmune disorder.

At the Neuropsychiatric Institute in Fargo, North Dakota, researchers are evaluating the importance of taste preference in determining the vulnerability to substance abuse.

At the John B. Pierce Laboratory in New Haven, Connecticut, researchers are working to determine the means by which cells lining the blood vessels' walls communicate with each other to convey messages about blood flow, thus, acting to prevent blockages such as might lead to stroke.

And at the Coriell Institute for Medical Research and the Wisstar Institute in Philadelphia, Coriell cells, human cells which were developed by us jointly, were carried into space last week on the Space Shuttle Endeavor and are being grown as we speak on the Space Station MIR to study the effects of microgravity on human cell growth.

Being thoroughly cognizant of your sermonette regarding the budget allocation process, I urge your support for the Ad Hoc Committee's budget proposal for NIH, and I thank you deeply for the opportunity to appear before you today.

Mr. Porter. Dr. Beck, thank you so much. We're sorry that you had to wait so long and we got so far behind. I'll try to do better in the future, is all I can say, and obviously, we'll try to do our very best to meet the terms of your testimony in terms of funding for research.

Mr. Beck. It was a very valuable opportunity for me to be convinced that the basic research the AIRI Institutes do is

even more valuable than we thought it was because it cuts across so many areas and so many of the stories, the powerful stories you heard today, are benefitted by the research that we do. A single research project can benefit many different diseases, and so basic research is truly the key, I believe.

Mr. Porter. I will lobby you for another second. The American public needs to understand this. They need to know it specifically, and you need to get the message out. I need to get the message out--we all do--to them, as to why this is so important to their lives, to the lives of other people in the world, and to the country and its future.

Mr. Beck. I agree completely.

Mr. Porter. Thank you very much.

[The prepared statement of David Beck follows:]

[Pages 662 - 671--The official Committee record contains additional material here.]

Mr. Porter. The subcommittee will stand in recess until 2:15 p.m.

Afternoon Session

Mr. Bonilla [presiding]. The subcommittee will come to order.

Chairman Porter will be along shortly, as will several other members on either side of the Chair, and Ms. DeLauro has arrived, I notice.

Thursday, January 29, 1998.

WITNESS

LINDA CHAVEZ, CENTER FOR EQUAL OPPORTUNITY

Mr. Bonilla. We will now begin hearing from our witnesses. As we begin the hearing, I want to remind witnesses of two provisions of the rules of the House. In addition to the written statement, nongovernmental witnesses must submit a curriculum vitae and a statement of Federal grant or contract funds they or the entity they represent had received. If you have any questions concerning the applicability of this provision or question as to how to reply, please contact the subcommittee staff.

In order to accommodate as many members of the public as possible, we have scheduled over 20 witnesses for each session and still are not able to hear from all who wanted to testify. Overall, we will hear from over 200 witnesses in this segment alone. As a result, we must enforce the rule limiting testimony to five minutes very strictly, just in consideration for all of those who are appearing before us. I'd like to ask that, as you testify, you keep this limitation in mind in consideration for the other witnesses that will follow you. This year, we have started using a timer, which you'll hear a little noise output here when your time expires.

At this time, I'd like to call Linda Chavez, president, Center for Equal Opportunity. Welcome, Ms. Chavez.

Ms. Chavez. Thank you very much, Mr. Bonilla. On behalf of the Center for Equal Opportunity, I'm privileged to be here to testify this morning on an issue that I know concerns you and should concern all Members of the United States Congress, and, indeed, all United States taxpayers. It is an issue that affects 3 million limited-English-proficient children in the United States, and it has to do with the Office for Civil Rights' enforcement under the Lau decision of provisions for the teaching of limited-English-proficient children.

As you know, Mr. Bonilla, in 1974 the Supreme Court decided that it was not enough simply to provide school children in the United States equal textbooks, the same teachers, and put them in the same classroom; that if those students did not speak English as their first language, that they needed to have extra help in order for them to be able to take advantage of the opportunity.

Since 1974, the Office for Civil Rights at the Department of Health and Human Services--and the Department of Education--has had a history of enforcing the Lau decision to require local school districts to provide not instruction in English, but rather instruction in the native language for hispanic children. I have submitted a written statement and included in that part of a chapter of a book I wrote on this subject, as well as two recent articles that I wrote for The Chicago Tribune.

OCR's approach to the problem oflimited-English-proficient children has been to mandate native language instruction, and most recently, the Office for Civil Rights has threatened the Denver public school system with a potential cutoff of all Federal funds unless Denver ceases reforms in its program which would include the introduction of more English into the curriculum for limited-English-proficient hispanic children in that school system. Indeed, there are more than a million hispanic children in the United States who are in programs that emphasize not the learning of English, but rather teaching in the native language. We might ask whether or not there is sufficient evidence to show that native language instruction is better than teaching children in English, and in fact we know that studies that have been done that look at the validity of all of the research in this area, show that in fact native language instruction does not provide better education opportunity to limited-English-proficient children.

Christine Roselle and an associate of hers, Keith Baker, who was formally with the Department of Education, has in fact looked at a survey of 72 studies of the issue of limited-English-proficient children that meet the normal scientific validation requirement and found that 78 percent of those studies show that teaching children in their native language is not only better for them than doing nothing, but that it may in fact be worse. The National Academy of Science just a year or so ago also took a look at the issue of how we teach limited-English-proficient children and showed that there is simply no reason, looking at the literature, to assume that teaching children in their native language is in fact better for them.

We also know from a tremendous amount of research that's going now on in the area of how human beings acquire language,

the basic area of neurology, that the earlier that children are exposed to a second language, the greater the likelihood is that those children will, in fact, be able to fully incorporate the syntax, the vocabulary, the grammar of that second language. So there's simply no scientific basis for the Office for Civil Rights to be mandating the teaching of limited-English-proficient children in their native language.

Well, if there isn't research to show why this is being the best method, perhaps there are other agendas, and I would contend that there is, indeed, a political agenda here having nothing to do with the needs of limited-English-proficient children or with the research in this area. Norma Cantu, who is the Assistant Secretary for the Office for Civil Rights, for example, was a lead attorney with the Mexican-American Legal Defense and Education Fund. That has promoted the teaching of native language instruction, and in fact she was involved in a court suit that led to the Denver public school system adopting its native language program, and yet she is now the person who is in charge of determining whether or not changes in that program meet OCR's definition of a proper title VI enforcement.

Also, the placement of children in these programs I believe is based more on a political agenda that is aimed at maximizing the number of children who are eligible. The criteria that's used by the Department of Education, and encouraged around the country, the criteria which looks not at the child, the language that the child speaks, but rather the language that is spoken in the home. So, for example, since I grew up as a young child in New Mexico with a grandmother and grandfather who spoke mostly Spanish to each other, I would have been eligible for such a program, even though that was not my language.

Moreover, standardized test scores are then applied, and as you know, a standardized test score is simply a way of determining the bell-shaped curve of distribution of the children taking the test, and the Office for Civil Rights determines that if you score below the 40th percentile, that you are automatically eligible. Forty percent of all children, even those who are monolingual English, will by definition score below the 40 percentile. I think this is a serious issue, and one that this committee should be looking at, and I would urge you, in considering the appropriations for the Office for Civil Rights, that you take these issues under very, very serious advisement.

Mr. Porter [presiding]. Ms. Chavez, I apologize to you for being delayed, and I thank my colleague, Henry Bonilla, for chairing the opening of the hearing. I didn't hear all of the testimony, but that part that I did hear I clearly and strongly agree with.

At a time when young people in scientific judgment can learn a language easily, and if they aren't instructed in that language early, then the chances of doing so diminish. So it seems to me that you're going down a path that doesn't lead to success nearly as well, even with good intentions perhaps, and I think we're beginning to understand because people like you and Henry and others are speaking the truth about these matters. We're gaining an understanding that we have to change the principles underlying these programs.

Ms. Chavez. Well, thank you very much, Mr. Porter.

Mr. Porter. Thank you for coming and testifying.

Mr. Bonilla.

Mr. Bonilla. Thank you, Mr. Chairman.

Ms. Chavez, as many people know, I'm an advocate of bilingual funds only to use in transitional cases to get kids to learn English as quickly as possible, and then to mainstream them. But this information that you're bringing forward to me is alarming. To think that an office couldhave their own political activist agenda is something that we're going to look at very, very closely this year.

My question that I have briefly is: How does their agenda that originates in Washington, how does that relate in some cases with what the parents want their children to learn in school?

Ms. Chavez. Mr. Bonilla, I will be happy to provide for you a copy, which I will ask be put in the record, of a survey that we did of hispanic parents nationwide. This was done through a reputable polling firm, an outstanding polling firm. The survey itself was taken in both Spanish and English.

What we found is that more than 80 percent of the hispanic parents who were surveyed wanted their children to be taught English quickly. They wanted their children's lessons to be taught in English so they could be spending more time learning how to speak, read, and write English. This is in direct contrast to what the Office for Civil Rights is requesting.

You also are, I'm sure, aware of the efforts that are going on in California to put an initiative on the ballot that will allow voters to make a determination about bilingual education in that State. My organization has been contacted by dozens of parents around the country, and in fact we will be providing to the committee written testimony from several of these parents in New Mexico, in California, and we hope also in Colorado, parents who object to what is being done with their children.

One of the most frightening things that we hear is that parents who do object go to their school district, go to their school, and rather than being given an objective analysis of what is best for their children, they are simply told, ``We know what's best for your children. Juan and Maria need to be kept in a Spanish language class.'' In some instances we're talking about children who come to school with English as their first language, and yet they, too, are forced to be put into Spanish language classrooms.

Mr. Porter. Ms. Chavez, we very much appreciate your testimony this morning. Thank you for being with us and giving us your view on this very important issue.

Ms. Chavez. Thank you, Mr. Porter.

Mr. Porter. I'd like to welcome a group of high school students from the tenth district of Illinois, which happens to be mine, and a visitor from Austria there, right back in the corner over here. Thank you all for sitting in with us and visiting.

[The prepared statement of Linda Chavez follows:]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 676 - 685--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

DR. PETER SCHWARTZ, SOCIETY OF GYNECOLOGIC ONCOLOGISTS

Mr. Porter. Dr. Peter Schwartz, president of the Society of Gynecological Oncologists, representing the Society.

Ms. DeLauro.

Ms. DeLauro. Yes. If I might just for a second, Mr. Chairman, with regard to the last panelist, I would hope that the committee would entertain information from both sides on the issue of bilingual education--there certainly are a lot of other people all over the country with various perspectives--and make a determination as to what is in the best interest of our youngsters in this country. I know, in all your fairness, that you will do that.

Mr. Porter. Ms. DeLauro, I apologize. I didn't know you wanted to be recognized.

Ms. DeLauro. That's okay.

Mr. Porter. I'm sorry.

Ms. DeLauro. No, I thought that was not the case, Mr. Chairman, but I, while not being shy, I'd like to say what I was going to say anyway. [Laughter.]

In any case, I have really a delightful task here, and that is that I am very, very pleased to be able to introduce to you today Dr. Peter Schwartz. I'm so delighted that he could spare some time to be with us today.

Dr. Schwartz is chief of the Elvohaven Hospital Section of Gynecologic Ontology and the president of the Society for Gynecological Oncologists. He literally and truly is one of the Nation's premiere researchers in the area of cancer--over 100 publications to his name, 136 to be precise.

He has particularly focused on the areas of gynecologic cancers such as ovarian cancer, which has been overlooked for such a very long time. We still don't have, as the committee knows, and I know the chairman knows, a dependable test to detect ovarian cancer at early stages.

Dr. Schwartz helped me to beat this disease, and he brings together a traditional commitment to patient care, which strengthened my own resolve, but with a confidence and professionalism and determination to explore every single new avenue in order to save lives. I know that he saved my life. I know that, with his commitment to increasing research, that we'll save so many others.

I thank you for the opportunity to introduce him. I thank you, Dr. Schwartz, for being here today.

Dr. Schwartz. Thank you, Congresswoman DeLauro and Congressman Porter. I am here today in my capacity as president of the Society of Gynecologic Oncologists, known as the SGO. The SGO is the only national medical specialty society devoted to the study and treatment of cancers of the female reproductive tract. The SGO has more than 750 members who

specialize in providing comprehensive care for women withgynecologic cancers, including prevention, diagnosis, surgery, and all subsequent therapy.

I'm extremely grateful for the opportunity to provide public witness testimony on behalf of the SGO in support of increased funding for the National Institutes of Health, and particularly the NCI. The written testimony I have submitted focuses on the instances of cervical, endometrial, and ovarian cancer and provides some examples of how additional research dollars are critically needed to improve prevention, diagnosis, treatment, and survival for the estimated 82,000 women who were diagnosed with a gynecological cancer in 1997.

My remarks this afternoon, however, will focus on ovarian cancer. Ovarian cancer causes more deaths than any other cancer in the female reproductive system. In 1997, an estimated 26,800 new cases of ovarian cancer were diagnosed, and an estimated 14,200 women died from ovarian cancer.

While early detection improves the chances that ovarian cancer can be treated successfully, early cancers of the ovaries rarely cause symptoms that women would notice or the symptoms are mistaken for menopausal ailments or intestinal illnesses. Early detection is complicated by the fact that the ovaries are deep inside the pelvis and cannot be seen directly without surgery. Small ovarian tumors are difficult for even the most skilled examiners to feel. In fact, there are no screening tests now available which are accurate enough to use in finding ovarian cancer early among women who have no symptoms.

Unfortunately, almost 70 percent of women with ovarian cancer are not diagnosed until the disease is advanced in stage. The five-year survival for these women is only 15 to 20 percent.

More than ever, there's a need for greater awareness and understanding of ovarian cancer. Now is the time to establish an agenda for more research into the areas that will lead to improved prevention, detection, and treatment of ovarian cancer.

The PHS Office on Women's Health, the SGO, and the NCI, in an effort to put ovarian cancer at the forefront of our Nation's cancer research agenda, sponsored a strategic planning cancer conference on new directions in ovarian cancer research on December 8 and 9, 1997 in Washington, D.C. The purpose of the conference was to outline the priorities for ovarian cancer research over the next five years. The conference participants identified the following eight critical components as the priorities for the strategy for attaining a greater understanding of the disease and for which a commitment to increased funding and investment in biomedical research should be pursued.

The first critical component is to support greater educational efforts for both the physician and patient communities. Due to the fact that early detection of ovarian cancer is so difficult and warning signs are so often confused with symptoms of other types of abdominal or pelvic ailments, it is essential that primary care physicians and gynecologists, as well as their patients, become aware of the potential early warning signs.

The second critical component is support for the development of a solid infrastructure for the study of ovarian cancer. Increased funding for ovarian cancer research is essential not only for RFAs and the creation of a specialized program of research excellence, otherwise known as a SPORE, but also for the recruitment and retention of young investigators as well as trained investigators from other fields. Innovative mechanisms to protect time for clinical scientists to conduct research are crucial, especially in the managed care environment that medical professionals now must practice in.

The third critical component is support for tissue procurement and banking. Tissue procurement and banking is an intrinsic part of clinical trials. By standardizing tissue collection and storage, we can then gather epidemiologic and follow-up data on ovarian cancer and correlate this data with molecular biological studies on the banked tissues.

The fourth critical component is support for identification of all genes expressed in ovarian cancers at all stages of the disease. This will facilitate the identification of molecular prognostic indicators, the identification of tools for early diagnosis, and the elucidation of the etiology of ovarian cancer.

The fifth critical component is support for the collection of data to evaluate the utility of current tumor markers such as CA-125 and current diagnostic imaging modalities on mortality of ovarian cancer in a multinational, randomized trial.

The sixth critical component is support for the development of a cohort study of patients at a genetically high risk for ovarian cancer.

The seventh critical component is support for an ongoing multinational evaluation of conventional therapy approaches to ovarian cancer.

And, finally, the eighth critical component, support for the development and evaluation of novel investigative approaches to ovarian cancer.

Congressman Porter, Congresswoman DeLauro, members of the subcommittee, I greatly appreciate your time and attention to the need for additional resources for research being conducted for improved prevention, diagnosis, and treatment for gynecologic cancers. The SGI and I look forward to working with you in the years ahead on behalf of women andtheir reproductive health.

I'd be happy to answer any questions.

Mr. Porter. The tyranny of the bell, Dr. Schwartz.

Dr. Schwartz. I hear it. [Laughter.]

Mr. Porter. Sorry, this is a new innovation for all of you who are testifying for the first time. We have not done this in the past. I don't know whether you had announced, Henry, that we were doing this. All right. Well, the reason is that it's simply because we have so many witnesses that want to testify.

Dr. Schwartz, you realize, I know, that this subcommittee has placed biomedical research at a very, very high priority in our deliberations, and you also know that Ms. DeLauro has been a leader on the subcommittee in pushing us on cancer research, and I know she will be in the future about any questions.

So thank you very much for coming to testify. Thank you so

much, sir.
    Dr. Schwartz. Thank you.
    [The prepared statement of Peter E. Schwartz, M.D., follows:]
    [Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 689 - 694--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

DR. ERROL CROOK, AMERICAN FEDERATION FOR MEDICAL RESEARCH
    Mr. Porter. Dr. Earl Crook, associate professor at the University of Mississippi Medical Center, testifying in behalf of the American Federation for Medical Research.
    Mr. Wicker.
    Mr. Wicker. Thank you, Mr. Chairman, and members of the subcommittee. It is my pleasure today to introduce to the subcommittee a very distinguished citizen of the State of Mississippi. Dr. Errol Crook is a native of Monrovo, Alabama. He received his undergraduate degree from Yale, and did his medical school at Columbia. He is currently an associate professor at the University of Mississippi Medical Center in Jackson, where he has conducted extensive research in the areas of diabetes and hypertension.
    Members of the subcommittee, you will soon realize why we are so delighted to have him at the University of Mississippi. Dr. Crook is going to testify today on behalf of the American Federation for Medical Research, and to discuss the challenges facing clinical research.
    Mr. Porter. Dr. Crook, we welcome you. Thank you very much for coming to testify.
    Dr. Crook. Thank you, Mr. Wicker, for your kind introduction.
    Good afternoon to the committee and Chairman Porter. The AFMR welcomes the opportunity to testify here today about the challenges confronting our Nation's clinical research effort.
    I am Errol Crook, assistant professor of medicine. I wish I were an associate, and I will be soon, I hope--at the University of Mississippi School of Medicine. The American Federation of Medical Research is a national organization of over 6,000 physician scientists, primarily medical school faculty members who are engaged in basic, clinical, and health services research.
    Our organization wants to express its deep appreciation for this subcommittee's strong support for the National Institutes of Health. However, it is important to assure that a significant portion of these additional funds be allocated to much-needed initiatives to strengthen NIH extramural clinical research programs. We commend subcommittee members Lowey,

Wicker, Hoyer, Pelosi, and DeLauro for their leadership in sponsoring H.R. 3001, the Clinical Research Enhancement Act, authorizing additional funding for new clinical research, career development, and research project awards. The AFMR urges this subcommittee to move forward this year and propose additional NIH funding to revitalize our Nation's clinical research efforts.

Through clinical research, basic science discoveries are applied to the study of human physiology to research on a disease or a condition or do an initial study of a potential therapeutic intervention. It is critically important that steps be taken immediately to address the problems confronting clinical researchers and their patients. These include the loss of a generation of young clinical investigators faced with enormous medical school tuition debt and absence of a structured, well-supported training and career development program; the inability of academic medical centers to sustain internal mechanisms of support for clinical research because of cost containment required by fierce competition in the health care marketplace, and the declining infrastructure for clinical research, most notably the insufficient funding provided to the NIH-funded general clinical research centers.

Funding is extremely limited for clinical research that may not offer a product payoff. Today, and for the foreseeable future, such research requires NIH funding. In addition, NIH funding is critically important for the training and career development of clinical investigators. In collaboration with Jackson State University and Tougaloo College, we at the University of Mississippi Medical Center are initiating a major study of cardiovascular disease in African-Americans, the Jackson Heart Study.

Our major difficulty in mounting and continuing this National Heart, Lung, and Blood Institute-sponsored study will be to recruit and sustain a sufficient cadre of clinical investigators to oversee the effort and interact with the patients.

In September of 1994, the Institute of Medicine of the National Academy of Sciences published a report on the opportunities and challenges confronting clinical research. The Institute recommendations are the foundation of the Clinical Research Enhancement Act, H.R. 3001.

More recently, in December of last year, the NIH Director's Advisory Committee on Clinical Research presented its report offering similar recommendations. Attachment 1, in the written testimony, is a side-by-side analysis demonstrating the close concurrence between H.R. 3001 and the Advisory Committee's recommendations.

The AFMR believes that this subcommittee must take action to provide additional funding for the initiatives that have been recommended by the Institute of Medicine, the NIH Director's Advisory Committee, and the 140 organizations that support H.R. 3001. This would require an additional $60 million, which is less than one-half of a percent of the NIH budget.

In addition, the AFMR urges the subcommittee to take steps to increase substantially funding for the NIH-sponsored general clinical research centers across the country. These safe havens

for clinical research are vitally important. Last year, in the report accompanying the Fiscal Year 1998 appropriations bill, this subcommittee expressed concern about the reductions made in the DCRC grants below Advisory Council-approved budgets. The subcommittee requested a report from the National Center on Resources as to the funding necessary to bridge this gap. For Fiscal Year 1999, the AFMR recommends a $215 million budget to bridge the average 25 percent cut below the Advisory Council-approved budgets for the general clinical research centers and to stabilize funding for personnel and training.

Please do not delay further. Just as you would move forward to rebuild the clinical research capacity on the NIH campus, please forward this year with much-needed investment in the extramural clinical research capacity of our Nation's academic medical centers.

Thank you for the opportunity to testify. I'd be happy to answer any questions.

Mr. Porter. Dr. Crook, thank you for your testimony. Let me say that the Chair does not, as a matter of principle, co-sponsor legislation that might appear before this committee, even though members of the committee don't share this philosophy. So the fact that I'm not a co-sponsor of H.R. 3001 doesn't mean that I'm not necessarily for it or strongly for it.

The problems that you raise of attracting new investigators and young investigators and keeping them, protecting academic medical centers, clinical research centers, who are under siege because of the change in the way we deliver health care services in the United States, managed care looking elsewhere because of the costs for a lot of their contracts--those are problems that we're very much aware of and want to be helpful on, and of course your final point about the clinical research centers and their funding is one that we take very seriously and we'll do the very best we can.

Dr. Crook. Thank you.

Mr. Porter. Thank you very much for testifying today.

Dr. Crook. Thank you.

[The prepared statement of Errol Cook follows:]

[Pages 698 - 710--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

JANNINE CODY, CHROMOSOME 18 REGISTRY AND RESEARCH SOCIETY

Mr. Porter. Jannine Cody, president, the Chromosome 18 Registry and Research Society, testifying in behalf of the Society. Ms. Cody.

Mr. Wicker.

Mr. Wicker. Thank you, Mr. Chairman.

Let me just briefly say that Dr. Cody is from San Antonio and is almost a constituent of my colleague, Henry Bonilla, a few miles away from the district there. She's currently a post-

doctoral fellow at the University of Texas, San Antonio, where, as you say, she's conducting research on chromosome 18 disorders.

I very much appreciate, Mr. Chairman, your moving Dr. Cody forward on the agenda this afternoon, so that I could be here for her testimony.

I have a particular interest in this disorder, and I think that some of the special voices that we may be hearing in the audience today are part of Dr. Cody's team. Some dear friends of mine from Mississippi, Lyle and Ruth Ann Williams, have a grandson, Michael Byce, born with chromosome 18 disorder. So I have a particular personal interest in this disease and in the testimony this afternoon.

Thank you so much.

Mr. Porter. Thank you, Mr. Wicker.

Dr. Cody.

Ms. Cody. Okay, thank you very much, Mr. Chairman andmembers of the subcommittee, and Mr. Wicker. Thank you for allowing me this opportunity to come here today and share some of our concerns with you.

My name is Jannine Cody, and I'm founder and president of the Chromosome 18 Registry and Research Society, the support group for families affected by chromosome 18 abnormalities. I live in San Antonio, Texas, as he said, and I'm accompanied by members of our board of directors from Chicago, Detroit, and some of our families that live in the D.C. area.

We're here today to ask you to re-evaluate the NIH funding priorities. Nationally, in our fervor to alleviate suffering and to ensure a long and healthy life, we've ignored our most needy and vulnerable citizens. We have focused our medical research efforts on prolonging the end of life without equal commitment to giving the people with mental retardation and developmental disabilities a complete life, a life of dreams and promise, and a life of independence instead of dependence.

Thirteen years ago, my daughter, Elizabeth, was born--here's her picture--with a severe cleft palate and cleft lip and foot abnormalities. A blood test revealed that these problems were caused by a chromosome abnormality called 18q-. This is a mental retardation syndrome caused by a missing portion of chromosome 18. The pediatrician gave us a photocopy from a medical textbook which made the following observation about our kids with 18q-:

It said, ``They are probably the most severely afflicted among carriers of chromosome abnormalities. They maintain the froglike position observed in infants and are reduced to an entirely vegetative and bedridden life.''

But for us, our most immediate concern was repair of her cleft lip and palate, and to date she's had 12 surgeries and is about at the halfway point in the repair process. However, her first four surgeries, all before the age of 3, were complicated by her failure to heal properly. We now know that her healing problems were caused by growth hormone deficiency which also causes short stature. The eight surgeries she's had since being on growth hormone replacement therapy have healed perfectly.

She's had to face numerous surgeries to repair the complications resulting from her early failed surgeries because no one ever asked a simple question: Why are kids with 18q-

short? So because of Elizabeth, growth hormone deficiency is now known to be a common feature of the 18q-syndrome, and hopefully, no child will ever have to endure the pain and trauma of unnecessary surgery and abnormal scarring.

It was this finding in my daughter that spurred me to find other parents and to see that research is done to determine the nature of our children's problems. I started the Chromosome 18 Registry and Research Society in an effort to bring families together who are affected by chromosome 18 abnormalities.

In order to ensure that the research done on these syndromes is clinically relevant and is translated into patient useful information, I earned a Ph.D. in human genetics, working on the 18q-syndrome. Our goal is to find treatments and not just supportive care for our children.

One of our main organizational goals is to establish a chromosome 18 clinical research center. We thought that if we as parents could gather preliminary data on the study of each of these syndromes, then these projects could move on to be federally funded. We would just have to get the ball rolling.

Our families have invested more than $700,000 to generate preliminary results and this has not been enough. It's not been enough because the pot of NIH money available to study these syndromes in the Mental Retardation branch of the NICHD is disproportionately small. It is disproportionately small compared to the number of people affected by mental retardation and disproportionately small compared to the proportion of mental retardation caused by chromosome abnormalities. Details about the budgetary inequities and social burden are presented in my written testimony.

Since 50 percent of mental retardation is caused bychromosome abnormalities, and chromosome abnormalities have defined genetic etiology, they are the logical starting place for unraveling the mysteries of learning differences and mental retardation. The study of chromosome abnormalities could open many new vistas in cognitive neuroscience. What we would like for you to realize is that, by studying chromosome abnormalities, you would not just be helping our families, but you would be opening the door to understanding mental retardation and developmental disabilities.

Chromosome abnormalities can serve as the key to understanding mental retardation and fulfilling the promise of the human genome project, which has provided us with the scientific opportunity. With the promise of increased NIH funding in the air, please consider directing those funding increases in ways which will equalize research for the currently underserved populations, such as those with mental retardation and chromosome abnormalities. These are areas of research which have great scientific promise in a field where there is currently little expenditure. These syndromes carry a significant social burden with lifelong health care costs and entitlement costs.

Thank you for the opportunity to testify before you today. I will be happy to answer any questions.

Mr. Porter. Dr. Cody, this subcommittee wants to do everything it can to help, and I think that the subcommittee has in the last three years, in the face of very difficult budgetary times, has put biomedical research at a very high level in the priorities that we fund.

Ms. Cody. We appreciate that very much.

Mr. Porter. I have to give you my sermonette at this point in time, all of you, because what we can do depends in the first instance upon what the Budget Committee gives us to work with. We're delighted to have you here telling us what we should do, but we want to direct you also to tell the Budget Committee what they should do.

Ms. Cody. Okay, we will do that.

Mr. Porter. Because if we don't get that kind of allocation, we can't do----

Ms. Cody. Right.

Mr. Porter [continuing]. The work that we think is necessary to be done.

There is obviously a lot in what you said to us that touches our hearts, but there's also hope because there's so much wonderful science going on out there, that we can't come close to funding all of it, and what we need to do is fund more of it. So we, I think, are committed to doing that, but we need help to get the resources to actually accomplish it. So if I can lobby all of you, do your utmost to help us get the resources that we need to accomplish the kinds of goals that you want us to accomplish, and together I think we cando a great deal to give our research scientists the tools that they need to have the breakthroughs that will solve these problems for the American people, and all people, actually.

So thank you for coming to testify.

Ms. Cody. Thank you.

Mr. Porter. We're going to do our utmost to do exactly what you want us to do.

Ms. Cody. Thank you very much.

[The prepared testimony of Jannine D. Cody follows:]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 714 - 721--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

ROSALIE LEWIS, DYSTONIA MEDICAL RESEARCH FOUNDATION

Mr. Porter. Rosalie Lewis, the president-elect, Dystonia Medical Research Foundation, representing the Foundation.

We're delighted to welcome our colleague, Louise Slaughter of New York. Thank you for joining us, Louise.

Ms. Slaughter. Mr. Porter, Mr. Manzullo, I'm delighted to see you both.

Mr. Wicker. Now just a minute.

Ms. Slaughter. Oh, Mr. Wicker, I'm sorry. [Laughter.]

I took my glasses off. Of course, I'm happy to see you.

Mr. Wicker. I can take a lot of things. [Laughter.]

Ms. Slaughter. Well, I'm so happy to be here with you this

afternoon, and I want to help you, too, to get more money from the Budget Committee, because I know you and I talked about this before, but we are right on the cusp of so many extraordinary discoveries in health care and in medicine, and it would be a shame for us to starve it to death at this juncture.

But I'm here this afternoon because I want to introduce a constituent of mine, Rosalie Lewis, who's the president-elect of the Dystonia Foundation, a research foundation. I've known her for many years, and all of us who know someone like Rosalie are very fortunate. She has dedicated herself to make a real difference in our community. She's been an active volunteer in the community for 20 years. She's leading the local chapter of the National Council of Jewish Women, speaking out and helping children with developmental disabilities, and encouraging support for families through organizations like the Jewish Family Services.

The issue that is nearest and dearest to her heart is dystonia research. Mrs. Lewis has four beautiful children, three of whom have been diagnosed with dystonia. This heart-breaking neurological disease can make walking and motor functions a serious challenge or renders them impossible. Mrs. Lewis has not only dealt courageously with her family's personal challenges of coping with dystonia, but has worked tireless to marshall resources to unlock the mysteries of this relentless and incurable disease. While researchers have recently made important advances in understanding dystonia, Mrs. Lewis is here to tell you why so much more needs to be done.

So I'm proud to introduce Rosalie Lewis of Pittsburgh, New York, the president-elect of Dystonia, and say again my thanks to you and Congressman Wicker from Mississippi, one of our finest.

Mr. Porter. Thank you, Representative Slaughter. We appreciate, Louise, your coming here and introducing Mrs. Lewis.

Ms. Lewis.

Ms. Lewis. Thank you very much, Congresswoman Slaughter, and hello again, Mr. Porter and members of the committee.

I am Rosalie Lewis, president-elect of the Dystonia Medical Research Foundation. It's my pleasure to be here today to tell you a little bit about dystonia on behalf of the Foundation.

First and foremost, I would like to thank this subcommittee for its generous funding of the National Institutes of Health in its Fiscal Year 1998 appropriations bill.

In 1985, the first of the three of my four children with dystonia was diagnosed. I had hoped that my 20-year-old son Benjamin, who was affected by dystonia since the age of 7, could have joined me today. However, dystonia has robbed him of the ability to walk unaided, to use his hands for any fine motor coordination like writing or playing his beloved guitar, and has now made speaking difficult. Like Ben, my son Dan, who is 17, first exhibited symptoms of this disorder at the age of 7, and like Ben, dystonia has now made walking independent a challenge.

The progression of early-onset dystonia is relentless and uncontrollable. That is why, on behalf of the 300,000 other

children and adults, I am asking you for your help today.

Dystonia is a neurological disorder characterized bysevere involuntary muscle contractions and sustained postures. There are several different types of dystonia. Generalized dystonia afflicts many parts of the body and usually begins in childhood. My sons Benjamin and Daniel have generalized dystonia.

Focal dystonias affect one specific part of the body. My son Aaron has a focal dystonia of the hand. Secondary dystonia is the result of injury or other brain illness.

There is no definitive test for dystonia, and many primary care doctors have never seen a case of it. It is estimated that 85 percent of those suffering with dystonia are not diagnosed or have been misdiagnosed.

Treatment for dystonia includes drug therapy, botulinum toxin injections, and several types of surgery. However, these treatments are met with limited and variable success.

My children with generalized dystonia take huge dosages of drugs, making cognition difficult. But with the choice between walking and not walking, they choose to tolerate the drugs' side effects. Daniel also receives injections now directly into his abducta muscles of the vocal cords with botox, and thank God, he has been having some moderate success.

Since 1977, the Foundation has awarded over 285 medical research grants, totaling close to $15 million. Among the more significant results of this research are the discovery this past year of the DYT1 gene, which is the gene responsible for early-onset dystonia. In 1995, the identification of the gene for dopa-responsive dystonia. In addition, several drug therapies have been developed.

The discovery of the gene for early-onset dystonia was made by Dr. Xandra Breakefield, geneticist at the Neuroscience Center of Massachusetts General Hospital in Boston, and her collaborators. This breakthrough came after two years of dedicated research and over $1 million of contributions made by the Foundation. With the discovery of this gene also came the identification of the protein which plays a crucial role in the chemistry of dystonia.

One of the Foundation's central goals is to educate the lay and medical communities about dystonia, so that people afflicted with the confusing symptoms of this disease need not go undiagnosed or misdiagnosed, as is so common now. We also continuously conduct and promote Medical Awareness Week, which this year will be taking place between October 11 and 18.

The Dystonia Medical Research Foundation recommends that the National Institutes of Health, the National Institute on Neurological Disease, Disorders, and Stroke, and the National Institute on Deafness and Other Communication Disorders be funded for Fiscal Year 1999 at a 15-percent increase over Fiscal Year 1998. This increase would be part of an overall request to double funding for the National Institutes of Health by Fiscal Year 2003. We would ask that this increase does not come from funding sources which would require budgetary cuts in other Public Health Service organizations.

Your help is desperately needed. Dystonia is the third most common movement disorder after Parkinson's and tremor. I'd like to repeat that: Dystonia is the third most common movement disorder after Parkinson's and tremor.

Hopefully, with the continuation of the necessary funding better therapies will be created which will help the hundreds of thousands of Americans who suffer from this debilitating disorder. Again, thank you for all the help that you have provided us in the past and for giving me the opportunity to speak here today. I would be honored if you had any questions whatsoever.

Mr. Porter. Mrs. Lewis and Representative Slaughter, we are going to continue to do whatever we can to possibly raise the commitment to research that can mean that 15 or 20 years from now, or sooner, that there will be no more cases of this disease.

I gave a short sermonette that I imagine you heard a minute ago. I want to add one thing to it. We often think that it's just the people here in this building that make public policy somehow, but we don't; we just ratify what people tell us back home. The message of this disease and others has to be gotten out there, so that people understand that it's such a serious matter that we need to mobilize national resources and that we need to put them into this kind of research. If we can all work on that--people intrinsically believe that, they have to know it specifically. They have to know why and how it's going to change things, and there's so much good science, as I said a minute ago, that is there. In fact, we are able to fund less and less of it, even though we're increasing funding more and more, because there's so much good science, that we need to get this message out to the American people that they need to impact each one of our offices saying: do this.

This idea of increasing, doubling research funding over the next five years is really something that we believe in and want to see happen. If that happens, it will happen here.

Ms. Lewis. Well, we're trying.

Mr. Porter. You're trying; we're trying. If we all work on it, I think we can achieve that goal.

Ms. Lewis. I appreciate that.

Mr. Porter. Thank you for coming to testify.

Ms. Slaughter. In the long haul, a healthier population will benefit us all, both financially and physically.

Mr. Porter. Absolutely.

Ms. Lewis. Thank you.

Mr. Porter. Thank you very much. Thank you, Louise.

Ms. Slaughter. It's a pleasure.

[The prepared statement of Rosalie Lewis follows:]

[Pages 726 - 732--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

SCOTT HODGE, REPRESENTING HIMSELF

Mr. Porter. Scott Hodge, the Grover M. Hermann Fellow, the Heritage Foundation, testifying in his own behalf. Mr. Hodge.

Mr. Hodge. Thank you, Mr. Chairman, distinguished members

of the committee. My name is Scott Hodge, senior federal budget analyst at the Heritage Foundation. As many of you may know, the Heritage Foundation is a nonprofit, nonpartisan research think tank. We accept no government funding whatsoever.

I suppose it's safe to say that my testimony, the tone of my testimony today will be slightly different than much of that you've heard today. I suppose I sort of feel like a heretic in a church service, but I guess because I'm here to remind us of the need for fiscal responsibility during a period, a fortunate period, of balanced budgets. Remarkably, because of the increased growth of the economy, we are able to nearly balance the Federal budget four years ahead of schedule. But, sadly, rather than encourage greater fiscal discipline, we see in many quarters of this town a decrease in fiscal discipline and a willingness to increase Federal spending--most notably, in some of the proposals by the White House two nights ago.

I think it would be a mistake to increase Federal spending and increase new programs without first fixing what ails existing programs. Balancing the budget is only the first step in fixing the fiscal health of the Federal Government. The next step must be reshaping Federal programs, so that they are capable of addressing the needs of the 21st century at the least possible cost to taxpayers. Too many government programs, as you know, were created to solve problems of another era, and reinventing these programs is not the answer. The American people do not want government programs simply to waste their money more efficiently. They want the problems fixed once and for all.

Three years ago, as you know, this subcommittee showed great courage in proposing the termination of 170 programs because they either showed no positive results, they were redundant, or they should be performed by lower levels of government. This is exactly the kind of litmus test that every committee in appropriations should apply to all of their programs. This is the kind of courage that I think it takes to restore fiscal discipline in the budget.

As you begin to craft this year's appropriations bill, I should hope that we can reinvigorate the themes that were brought forward so powerfully in that bill three years ago, and there are many challenges ahead. I believe discretionary spending should be cut, not increased. This year discretionary spending in this particular appropriations bill has increased by $5 billion above last year's level. That's 9 percent increase--three times the rate of inflation. I think that balancing should not be used as an excuse to raise spending. Actually, it should be a chance to tighten our belts a little more.

Second, I don't believe the committee should fund programs that have not been authorized or in which their authorizations have expired. The Congressional Budget Office now tells us that Congress this year approved $115 billion for unauthorized programs in Fiscal Year 1998. Roughly $8 billion of that amount fell into the programs under the jurisdiction of this committee. If Congress had had the fiscal discipline perhaps not to fund just a fraction of those unauthorized programs, perhaps the budget would be in balance today, rather than $5 billion deficit.

Lastly, I believe the committee must confront the problems identified by the General Accounting Office, the agencies' Inspectors General, across these programs. The problems identified range from severe financial mismanagement, lack of management accountability, widespread program duplication and fragmentation, poor stewardship of government assets, and obsolete programs living on forever.

Many of these, of course, are familiar to this committee, I'm sure. The 165 job training programs scattered across government agencies, 131 juvenile programs at a cost of $4 billion a year. The President seems like he's ready to initiate more of these programs. Education, 788 programs, and counting. Statistical agencies, kind of an obscure little part of the budget, there are 70 different agencies in government that provide statistics, including many under this committee's jurisdiction.

Lack of accountability is legendary in many of these programs, unfortunately. The safe and drug-free schools program, which many people would support, unfortunately, has seen monies misspent, such as in Michigan, where $81,000 was spent to purchase giant plastic teeth and toothbrushes. One point five million of this money was spent on a human torso for a class, and $11,000 of this money was spent on bicycle pumps.

While that's the absurd, there are very serious issues at hand as well. In the job training and employment services, for instance, the General Accounting Office found that almost 40 percent of Federal job training programs could not even count accurately how many people were going through their doors, and another 50 percent of these programs could not collect data on whether participants had obtained jobs after they completed the program. Of course, this is just the tip of the iceberg.

Let me conclude by saying that the Heritage Foundation last year prepared ``Balancing America's Budget,'' which used many of the same themes that you used in preparing your appropriations report three years ago: reduce and eliminateobsolete programs, consolidate redundant programs, and transfer programs that are most appropriately done by the States back to State and local governments. I think this is a fine opportunity, with a balanced budget, to restore fiscal discipline rather than let it loose.

Mr. Porter. Mr. Hodge, let me say that I couldn't agree more with the general theme of what you're saying. I began my congressional career talking about the framework of fiscal responsibility, and if we don't operate within that framework and make our decisions within that framework, obviously, we will have gone, as we have gone for the last 30 years, in a very, very poor direction for the whole country. Everything we do has to be done with an idea that we work off a balanced budget and that, within that budget, we choose priorities.

We also know that government has grown without restraint for a long, long time, and we're doing a lot of things we shouldn't be doing. We have programs that the Federal Government shouldn't be engaged in. We have programs that the Federal Government is engaged in that don't work. I can tell you--and I think this is true on all the Appropriations subcommittees--the environment here has changed greatly. Everything that we talk today is: do we get results for

people?--not how many people are in the program, how many dollars are spent, do we have so many centers. We talk about what happens to the individual who's supposed to be being served by that program. Is that individual starting unemployed, let's say? Is he getting trained? Is he getting a job? Is he keeping the job? Is he supporting his family? That's the thing we're looking for.

We've just sent letters out, you may be interested, to each of the three Secretaries of the departments over which we have jurisdiction and each of the agency heads; we sent them out a couple of months ago actually, and we said, when you come in to testify, include in your testimony at the most prominent place the results that you're getting for the money that you're getting, because that's what we're going to ask you and that's what we want to know.

We also have the GAO coming in to testify----

Mr. Hodge. Right.

Mr. Porter [continuing]. Looking at those programs that are under their jurisdiction and commenting, in their judgment, are they getting results from money? So we're doing it independently of the department or agency that is coming in to testify.

GPRA we have been harping on a great deal last year; we will be on it this year. We're not to the results stage there, but I think the law is in place that will show us the budgetary guidelines that will help us get there eventually, and we're very strong on that.

I think the subcommittee has shown that we know how to eliminate programs; you said so yourself.

Mr. Hodge. Absolutely.

Mr. Porter. There's programs that don't work. We have not been joined by our brethren and ``sistren'' in the Senate, as we would have liked to have been, but I think that we know that there are a lot of programs that really don't work and we do our best to try to get rid of them or consolidate them into broader programs that serve broader constituencies.

I'm not sure--I am sure; I can't agree that we shouldn't fund programs that are not authorized. Unfortunately, authorizers don't do their work, and they see our bills as vehicles for their being able to put on policy choices that they wouldn't take up in their own subcommittees. They'll take them up on the floor in an amendment, but they never take them up in terms of a bill. So there's always this tension between authorizers and appropriators. We can't force them to do their work; they have to do. Programs should be authorized; the whole concept is to have authorized programs, but if we have to wait for them, I'm afraid nothing would ever get accomplished. They choose to avoid contention and put it onto our bills, where it raises its ugly head and we keep saying, leave these things off of our bills; do your own work, but we never get there.

The careers legislation has passed the House strongly. That will get rid of all those 163 job training programs and get us into a few good ones that we can evaluate easily, that will reach out to people and give the help to them that they need, and get results.

The bottom line on all of this is that our job is to choose within a framework of fiscal responsibility a balanced budget,

priorities for our country, and so I don't think what you were saying is at all at odds with what people here are saying. They're simply saying, among those priorities, these are the ones we believe are the most important priorities. It's your job to take the responsibility for fitting them within that framework and making certain that we get ourselves to a balanced budget.

I'd like to say that Congress has done so well that we've gotten to a balanced budget; we'd all be lying to ourselves if we said that. Congress has helped. What has gotten us to a balanced budget, and we're about to get there, I think, is a really strong economy that is performing beyond anybody's expectations, and we're all saying, how can we keep this thing going and make certain that it continues into the future? Because if it does, then we will have resources to do the kind of research that people are saying we really ought to do.

In respect to biomedical research, this is something that really cannot be funded in the private sector. We'd like to think it could. It's basic research. It's not applied research. Most of it is basic research. It's the foundation upon which our pharmaceutical and biotech companies in America can build those pharmaceuticals, those procedures, those new ways of approaching disease that get results for people. So this is something government has to do. I think government not only has done this well over a long period of time, but it is an investment that pays for itself a thousand times over.

I will mention only one thing that is mentioned often. The health care cost savings from the discovery of the Salk vaccine has paid all of the costs of the research conducted through NIH over its entire 50-year history, one discovery. If you look at the tens of thousands of discoveries that we've had through NIH-funded research, you know that this is really cost-effective investment, and I think something that the American people very, very strongly support--but within a framework of a balanced budget. I sure agree with you.

Thank you very much for your testimony. I'm sorry to give you my long sermon there----

Mr. Hodge. I appreciate it.

Mr. Porter [continuing]. But I think we're doing our job, or at least we're certainly trying hard to do it.

Mr. Hodge. Thank you.

[The prepared statement of Scott Hodge follows:]

[Pages 737 - 748--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

POLLY SPARE, VOICE OF THE RETARDED

Mr. Porter. Polly Spare, president, the Voice of the Retarded, testifying in their behalf.

The Chair recognizes Mr. Istook.

Mr. Istook. Thank you, Mr. Chairman. I'll be very brief.

I appreciate Ms. Spare taking the time to be with us today. Where do you come from, Illinois?

Ms. Spare. No, my offices are in Illinois; I live in Pennsylvania.

Mr. Istook. Okay, I understand. Your office is in Illinois. I knew that would be of interest to the chairman.

Ms. Spare. I hope so.

Mr. Istook. Ms. Spare has been involved in efforts on behalf of the retarded, both as a mother and as someone who cares very deeply about the needs and concerns of others who either are retarded or have retarded persons in their family or among their friends. I think she has an important message to make sure that our well-intended efforts don't become misguided efforts.

I appreciate your taking time to be with us.

Ms. Spare. Thank you, sir. I appreciate the introduction.

Mr. Chairman, members of the subcommittee, I appreciate the opportunity to testify before you today about Voice of the Retarded and our experience with State protection and advocacy, developmental disability councils, and university-affiliated agencies. The issue of accountability among these groups has been of great concern to me, as president of Voice of the Retarded, as a parent of two profoundly retarded adult family members, and a tax-paying citizen who is painfully aware that my tax dollars may be financing activities aimed at eliminating developmental centers as one quality residential option from most disabled population.

My concern stems from the fact that the three programs I had mentioned engage in activities that promote total deinstitutionalization. The litigation activities of protection and advocacy agencies are of most concern and have directly resulted in the closure of some State-operated facilities. I will continue to refer to the three groups as the DD Act programs. Established by the Developmental Disabilities Assistance and Bill of Rights Act, the DD Act, they are authorized to receive Federal funding through the Department of Health and Human Services: over $108 million in Federal dollars in 1997, the same amount, reportedly, for 1998.

With all Federal grants, funding is appropriated with conditions imposed. There are two conditions of the act that I feel have not been met and warrant further investigation. The act's amendments of 1993 resulted in House Energy and Commerce Committee Report 103-378. Report language indicated that the act not be read as a Federal policy supporting the closure of residential facilities. The committee clarified what, in fact, mirrors VOR's mission. Many, but not all individuals with mental retardation are appropriately served in community-based residential settings. The act's statutory language under policy also places, as a condition for funding, the recognition that individuals and their families are the primary decisionmakers regarding the supports received and the policies developed on behalf of individuals with mental retardation.

There is growing evidence that deinstitutionalization is not in the best interest of all individuals with MR. VOR is learning of higher abuse, neglect, and mortality rates for individuals inappropriately and hastily transferred from developmental centers to community-based centers. The national

leaders of the DD Act programs, with the support of the former Commissioner of the Administration on Developmental Disabilities, Robert Williams, worked closely with VOR to address the lack of quality assurance standards and community programs. The progress that we made had less to do with communication and cooperation, but it was a worthwhile objective. Former Commissioner Williams also devoted agency funds for a more successful national project which I co-chaired, aiming at empowering parents. We are truly grateful for his open mind and willingness to work with VOR to enhance mutual respect and a cooperative agenda.

Some State DD Act programs continue to leverage their Federal dollars to help accomplish total deinstitutionalization. Protection and advocacy agencies have filed class action lawsuits in California, Connecticut, Maryland, New Mexico, Utah, Florida, Iowa, Washington State, and twice in Michigan, and served as intervenor in a Texas class action suit. I know of no similar action to correct the widespread programs plaguing some community-based programs.

In other DD Act programs, some other DD Act programs also engage in anti-institutional programs, using their Federal dollars. This year the Utah Governors Council for People with Disabilities, a DD Act program, will spend over $203,000 for legislative advocacy. Washington State, New Mexico, and Arkansas councils offer similar examples of lobbying activity.

Are Federal funds actually being used for these activities prohibited by the DD Act and other Federal laws? Whether or not the DD Act programs use public or private funds for their lobbying activity, the Federal grants certainly free up other funds to pursue deinstitutionalization interests.

VOR receives absolutely no public money, State orFederal. I was provided the opportunity to testify before the Subcommittee on National Economic Growth in June of 1995 on a similar topic: lobbying by groups receiving Federal funds. I stated then, and I state now, there is a larger question that looms: just how much Federal money are these groups receiving, and how are they held accountable for the use of these funds? How does the Federal Government assure that the money it invests in groups is used as intended?

It is an answer even the Secretary of the Department of Health and Human Services, Donna Shalala, has a difficult time answering. In response to a written inquiry regarding the amount of HHS appropriations spent on class action litigation against State-operated facilities, sent by Representatives Edwards and Wamp, Secretary Shalala responded, ``Program information on how individual cases are resolved indicates that very little money goes toward litigation.'' There's a great concern that the Secretary's records do not reflect the class action litigation activity in nine States which appears contrary to the directives of the DD Act. This is especially appalling when one considers the very facilities being sued are certified and funded through another HHS program, medicaid.

The executive director of the National Association of Protection and Advocacy Systems wrote an angry letter to VOR stating, quote, ``Just because you and your colleagues do not like the results of our activities does not mean that funds have been misspent.'' What he is forgetting is that every taxpayer, including VOR's members, must have the opportunity.

We understand that these groups objected to language that was submitted last year, and it was dropped. We wonder what there is to hide.

I thank you, Mr. Chairman, for your willingness to take a closer look at this issue. It deserves your serious consideration. I thank you and members of the subcommittee for your attention.

Mr. Porter. Ms. Spare, I'm sure that you're aware that at the heart of this issue is the underlying law----

Ms. Spare. Yes.

Mr. Porter [continuing]. Over which we don't have jurisdiction. On the other hand, we do have jurisdiction over the funding of the advocacy line items, and this is a point that I feel certain that Representative Istook is going to raise in our markup, if not before. My own experience is that I agree with most of what you've said, that there are some serious problems in this area that need to be addressed. We always hope our authorizing brethren and ``sistren'' will address them, but, as I said to the previous witness, often they don't, and that leaves it to us to attempt to do what we can about it. So I think the issue will be raised in our markup and we'll see what might happen among the subcommittee members.

Ms. Spare. I appreciate that very much.

Mr. Porter. Thank you for testifying.

Ms. Spare. Thank you.

Mr. Porter. Thank you.

[The prepared statement of Poly Spare follows:]

[Pages 752 - 764--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

RUSSELL J. STRATTON, THE AMERICAN ASSOCIATION OF DENTAL SCHOOLS

Mr. Porter. Russell J. Stratton, D.D.S., dean of the University of Oklahoma College of Dentistry, testifying in behalf of the American Association of Dental Schools. Dean Stratton.

Dr. Stratton. Thank you, Mr. Chairman. I'm Russell Stratton, Doctor of Dental Surgery and dean of the University of Oklahoma College of Dentistry. On behalf of the American Association of Dental Schools, I'm pleased to have the opportunity to present our Fiscal Year 1999 funding recommendations for the health professions training and research programs, which are especially important to dental education.

Mr. Chairman, at a time when many decry the shortage of primary care health professionals, and in a search for programs that will attract generalists, we're very proud of the general dentistry residency program which is a cost-effective primary care success story. General residency dentistry training provides graduates with primary care training and clinical experience to serve the broad community of patients. As you

mentioned earlier, results are what count. In this particular case, 87 percent of those students who receive general dentistry training remain in primary care practice, and these dentists, who have had the benefits of this training, make fewer referrals to dental specialists, and that's especially important in rural and underservedurban communities, where logistically and financial barriers make specialized care unobtainable. So it is a success story.

At my school, the Federal investment in this primary care training program means that many low-income children see a dentist for the very first time. The general dentistry residency programs provides a significant amount of free dental care through the Friendly Smiles Program, in which needy children are identified by the county and referred to our dental school clinic for treatment and preventive oral health services.

Our residency program was created through this Federal start-up grant in the late 1980s, and it has been self-sufficient ever since. In fact, it has enlarged at its own expense with no additional funding from the Federal Government.

The AADS urges the subcommittee to fund this cost-effective and proven primary care program at $4 million in Fiscal Year 1999. We would also urge the subcommittee's support for expanded funding for this program to accommodate pediatric dentistry, children's dentistry, training, if this change is adopted through the reauthorization process.

Next, the Ryan White HIV/AIDS dental reimbursement program accomplishes two major Federal objectives in the fight against AIDS: first of all, support for essential oral health services for patients of limited means and, secondly, clinical experience for dental students and residents in the care and management of people living with HIV/AIDS.

The Ryan White HIV/AIDS dental reimbursement program represents a true partnership between the Federal Government and dental education programs in which the Government partially offsets the cost of these programs incurred by serving by disproportionate share of indigent AIDS patients. However, because the award we receive from this program covers less than 50 percent of the uncompensated costs we incur, our dental schools are very concerned about our ability to maintain this current level of service in our communities.

Unreimbursed costs will continue to rise as the number of HIV patients increase and as the HIV/AIDS population lives longer. Very early on in the epidemic, dental care was directed toward eliminating infection and pain using procedures which had the least likelihood of exacerbating the patient's already fragile condition. But with the advent of multiple-drug therapies, many patients are living longer, and they require an increased scope of dental intervention. Patients now need periodontal procedures, or gum therapy; they need root canals and advanced restorative procedures such as crowns, bridges, and dentures. The AADS recommends a $1.2 million increase for the Ryan White HIV/AIDS dental reimbursement program, resulting in a total budget of $9 million in Fiscal Year 1999.

We also strongly support the National Health Service Corps scholarship and loan forgiveness programs. In recent years, the Congress recognized the need to increase dental participation

in the National Health Service Corps. There has been some progress in meeting the dental demand for loan repayment awards, but the agency still has not awarded any dental scholarships in the recent several years. We hope the subcommittee will renew its efforts to encourage the National Health Service Corps to expand its oral health initiative.

The AADS also urges your continued strong support, for title VII health professions programs play a crucial role in our ability to recruit and retain minority and disadvantaged students in dentistry. We request the funding levels for these programs recommended by the Health Professions and Nursing Education Coalition, of which AADS is a member.

Finally, Mr. Chairman, on behalf of the AADS and the University of Oklahoma, I want to express our gratitude for your leadership in the area of biomedical research. We endorse the testimony of the American Association for Dental Research regarding priorities in funding for the National Institutes of Dental Research in Fiscal Year 1999.

Thank you for the opportunity to testify. I'd be pleased to answer any questions you might have.

Mr. Porter. Dr. Stratton, thank you for your good testimony.

One comment: Mr. Bonilla of our subcommittee has been one of the strongest advocates of the health professions. You need to talk to the people over on the other side of the rotunda about that, though. The Senate has not been nearly as strongly supportive as we have, and I think that if you can get a chance to talk with them, it will help.

Dr. Stratton. We'll give it our best shot.

Mr. Porter. Thank you, Dr. Stratton.

Dr. Stratton. Thank you.

[The prepared statement of Russell Stratton follows:]

[Pages 767 - 778--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

JEFF JACOBS, AIDS ACTION COUNCIL

Mr. Porter. Jeff Jacobs, director of government affairs, representing the AIDS Action Council.

Mr. Jacobs. Mr. Chairman, members of the subcommittee, I wanted to start by introducing my colleagues, Javiar Salizar and Julio Abru who've joined me here at the table.

I'm Jeff Jacobs, director of government affairs for the AIDS Action Council, the national voice for over 2,400 community-based AIDS service providers. The council does not receive any Federal funding. Our work is supported by our members and individual donations.

This subcommittee is directly responsible for the dramatic advances in the care, treatment, and research of HIV disease. The advances of the past few years would not have been possible without the funding this committee has appropriated. It is

clear that your investment in HIV and AIDS programs is beginning to return big dividends. AIDS deaths are dramatically declining. Powerful new drugs have restored health and hope to hundreds of thousands of people with the virus, and research is progressing on new drugs and vaccines to treat and prevent HIV disease. In fact, the research you invested in at NIH earlier in the decade is translating into the care and treatment provided by the Ryan White Care Act. Its emphasis on early treatment, comprehensive health services, and the provision of drugs is literally saving people's lives. Your continued investment in the Ryan White Care Act is urgently needed.

Despite the existence of Federal AIDS programs such as the AIDS Drugs Assistance Program, Medicaid serves as the foundation of AIDS care through its provision of both comprehensive health care and drug therapies, however, most low-income individuals who are HIV positive are not eligible for Medicaid because they do not meet the programs disability standards or other categorical eligibility requirements. Low-income people with HIV must get sick with AIDS before they qualify for Medicaid. Not being eligible for Medicaid contradicts the need that HIV positive individuals have for access to the new treatments and care. Early intervention for people with HIV is now accepted as a standard, recommended by NIH, and is cost effective.

You may be wondering why I'm mentioning Medicaid, Mr. Chairman. This year, AIDS Action proposes that this committee allocate funds in the health care financing administration's budget to support a Medicaid demonstration project for States that choose to pursue an expansion of Medicaid eligibility to low-income HIV positive individuals.

Despite all the progress, there is disturbing news that demonstrates the urgent need for new investments in prevention. According to a new study co-authored by Yale University, 87 percent of young people do not believe they are vulnerable to getting the AIDS virus. The survey also found that over half the respondents could not name HIV risk factors. These startling statistics could be one reason why the CDC estimates that between 40,000 and 80,000 Americans will be infected with the HIV virus in 1998.

Preventing HIV infection must be a national priority. People become infected with HIV either because they do not realize they are at risk or do not really know how to protect themselves from the virus. New targeted prevention efforts are urgently needed to prevent new infections. Increased funding for the CDC's HIV prevention efforts will enable States and localities to implement locally determined prevention plans developed by health departments and the community. The HIV prevention community planning process gives States and localities the flexibility they need to design targeted prevention strategies. It is far less expensive to prevent someone from becoming infected in the first place than to care for that person once they are infected.

This raises the need for our Nation to get dirty needles off our streets. A 1997 NIH consensus panel concluded that needle exchange programs prevent the spread of HIV and do not increase illegal drug use. Secretary Shalala must retain her authority to federally fund these programs which have been

endorsed by the American Medical Association and the American Public Health Association.

Last but not least, we urge this committee to increase funding for the substance abuse treatment block grant. Much of the disproportionate increase in HIV infection rates among women, communities of color, and adolescents can be attributed to substance abuse. Increased funding for substance abuse treatment is desperately needed to help slow the spread of the virus.

In conclusion, we urge this committee to continue to provide leadership by increasing funding for these programs that save lives. Thank you for this opportunity to testify.

Mr. Porter. Mr. Jacobs, the subcommittee has certainly put Ryan White, the public education portion of the effort to prevent AIDS and others at a very high priority. I'm sure we will continue to do that. At the moment, as you know, on the needle exchange issue, there was an attempt to address that that really left the issue in the hands of the authorizing committee, and I think they have six months in which to act. I met with Dr. Bealenson who's running a very fine program in Baltimore that impressed me a great deal, and we hope that we can that issue resolved sometime soon and reasonably. I think you're exactly correct; that's a very important aspect of this that we need to pay great attention to. Thank you for testifying today.

Mr. Jacobs. Thank you, Mr. Porter.

Mr. Porter. We appreciate it very much.

[The prepared statement of Jeff Jacobs follows:]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 781 - 786--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

DR. GARABED EKNOYAN, NATIONAL KIDNEY FOUNDATION

Mr. Porter. Garabed Eknoyan, M.D., president, National Kidney Foundation, Professor of Medicine at the Baylor College of Medicine in Houston, Texas, testifying in behalf of the National Kidney Foundation. Dr. Eknoyan.

Dr. Eknoyan. Chairman Porter, thank you. I'm Garabed Eknoyan, president of the National Kidney Foundation, otherwise known as the NKF, the Nation's largest voluntary health organization devoted to the care of patients with kidney disease as well as the prevention and cure of diseases of the kidney and urinary tract.

I'm here today representing more than 30,000 lay and professional volunteer constituency of the foundation. The NKF is a member of the Council of American Kidney Societies, and we support the testimony that has or will be presented by the

other members of the council: the American Society of Nephrology, the American Society of Pediatric Nephrology, the American Society of Transplant Physicians, and the Renal Physicians' Association.

The National Kidney Foundation is most appreciative of the support that the committee has provided to the National Institute's of Health, NIH, during the last few years. We know that the members of the committee have been faced with difficult funding decisions for many worthy programs, and we thank you for making the NIH a priority. We are particularly appreciative of the 7.5 percent increase that the committee provided to the National Institute of Diabetes and Digestive and Kidney Diseases, NIDDK, for the Fiscal Year 1998.

Resolutions have been introduced in the House and Senate in support of doubling the funding of NIH over five years. We are encouraged by this broad and growing support throughout Congress. We urge the appropriate committees including the House and Senate Budget Committees to support this effort through the identification of additional resources beginning in Federal year 1999. This additional funding is essential to maintain our country's lead in the scientific investigation at a time when traditional sources of funding from the mental investigation and clinical research are diminishing and threaten to disappear--and I am sorry if I took this out of your sermon, Mr. Chairman.

For Federal year 1999, we would like to request a 15 percent increase in the appropriation for NIDDK. This commitment of additional resources is needed to continue the support of new opportunities for improving the health of Americans which by medical research has provided and continues to offer today. To that end, we would like to recommend some new opportunities in research and challenges in the area of kidney disease and to solicit your support for them.

Today, I would like to discuss two of the more important of these issues. Others are listed in the statement that was submitted. The first is proteinuria which is protein in the urine. There are 300,000 Americans with a irreversible kidney failure or end-stage renal disease, commonly termed ESRD, who require dialysis or a transplant to survive. We estimate that there are ten times as many individuals who have detectable protein in the urine which is an early indication of progressive kidney disease well before the presence of any other clinical or laboratory evidence of the problem. These Americans should become the focus of new attention for intervention and prevention. If these individuals with early kidney disease manifested by protein in the urine who are more likely to progress to ESRD are not attended to their cause will be downhill. More importantly, there is a much larger number of individuals who have protein in the urine, whose kidney disease will not progress to ESRD, but who are still at greater risk of heart attack and stroke than Americans without evidence of protein in the urine. How many? No one knows for sure right now, because not enough work has been done in this important public health area. We estimate the numbers to be in the millions, somewhere between 10 and 30, and it's hard to estimate it exactly. Nevertheless, very few of these individuals are identified or receive the care and attention

that could prevent their morbidity and premature mortality. We need to know more about the incidence and prevalence of proteinuria as well as the efficacy of the interventions which could address this public health problem.

The National Kidney Foundation is strongly committed to that goal. We recommend that the kidney division of the NIDDK be encouraged and provided support to gather basic epidemiologic information on this high risk segment of the population and to accept explore the appropriate strategies for the early identification and treatment of those at risk.

The second issue I'd like to cover briefly is that of nutrition. Other than age, nutritional status is the most potent predictor of mortality in patients who are on dialysis. Unfortunately, malnutrition is a common complication of chronic dialysis patients and occurs in 40 percent of these individuals. These poorly nourished patients are more susceptible to infection and are more likely to be hospitalized than other patients. We recommend that the NIDDK sponsor a demonstration project in conjunction with the health care financing administration which would document the efficacy of the various interventions that are currently available in improving the nutritional status of end-stage renal diseased patients.

Mr. Chairman, I hope that this testimony has emphasized the importance of research and its potential for preventing kidney disease and improving the lives of kidney patients. I'd be pleased to answer any questions you may have or to provide any additional information the committee may wish.Thank you again for this opportunity to address the committee.

Mr. Porter. Dr. Eknoyan, you have helped to educate us as so many of us our witnesses do. I sit here and, I think, gain a great deal more than any of you do, because you give me insights into what is happening in your various fields of medicine, and we have so many people of prominence like yourself who come before the committee that it's a real education for me. We hope to translate that knowledge into actions that help people in their lives, and we very much appreciate your coming to testify. My wife suffers from diabetes; obviously, I'm focused on the risks that are inherent in that disease, and one of which is severe kidney problems, and so I'm very appreciative of the opportunity to hear you and to know what your concerns are. We will do our best to meet them, and thank you for coming to testify.

Dr. Eknoyan. Thank you very much.

[The prepared statement of Garabed Eknoyan, M.D., follows:]

[Pages 790 - 797--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

MARY KAYE RICHTER, NATIONAL FOUNDATION FOR ECTODERMAL DYSPLASIA

Mr. Porter. Mary Kaye Richter, executive director of the

National Foundation for Ectodermal Dysplasia, representing the foundation.

Ms. Richter. Thank you, I'm always delighted when someone can say that name correctly.

Mr. Porter. You see how I'm getting educated here?

Ms. Richter. Yes, and, obviously, our previous visits have done exactly that.

In the past, I've talked a great deal about the ectodermal dysplasia--as you may recall, these are individuals who don't have a lot of hair, teeth, sweat glands, and nails--but today, I want to be a little more general in my comments as I see some programmatic concerns regarding rare conditions in and of themselves.

Through this hearing, you will listen to many individuals who espouse the doubling of the budget for the National Institutes of Health within the next five years and to begin that process with a 15 percent increase for year 1999, something with which we certainly agree. While some people would encourage you to earmark dollars for specifics of these entities, I would urge you to leave such decisions with the leadership of the NIH. It would indeed be unfortunate if research funding was prioritized by the effectiveness of lobbying rather than the effectiveness of science.

Once the diagnosis of a rare condition has been made, families encounter incredible challenges as they search for useful treatment information and knowledgeable care providers. Only the savvyest will make their way to organizations like ours. What happens to those families for whom no advocacy organizations exist? What happens when there are no available clinicians to make a diagnosis? What happens then when the effects of a condition exacerbate as a result? What happens when there's no place to turn, and you have no hope? How does it feel to bury a child?

In 1988, the National Commission on Orphan Diseases conducted a survey that indicated that 46 percent of the families affected by rare conditions endure from one to five years of searching before arriving at a diagnosis.

There is an office that is in a position to make a difference for families in such dilemmas, the Office of Rare Diseases within the NIH. Currently, there are more than 100 special research centers as identified by individual NIH institutes across the United States. I am asking you to enable the Office of Rare Diseases to select a minimum of 15 of these as diagnostic research centers for rare disorders that would focus on diagnosis and treatment.

A key function of the office of the rare diseases is the sponsorship of scientific workshops. One workshop focused on the ectodermal dysplasias. It was a landmark event as the National Institute of Dental Research, The National Institute of Arthritis, Muscle, Skeletal, and Skin Diseases, and the National Institute for Child Health and Development along with the Office of Rare Diseases joined together as co-sponsors. The symposium was a revelation to the SNBs as the overlap of key biological issues became apparent. It is clear that improved understanding of the developmental biology associated with ED with help unlock the doors of knowledge to human development.

Currently, the Office of Rare Disease sponsors, or co-

sponsors, approximately 30 workshops per year. With thousands and thousands of rare conditions, the number of workshops must be increased. Increasing the budget of the ORD by just $500,000 for workshops would significantly increase the number of rare disorders that are examined each year.

The Office of Rare Diseases could also serve as a much needed focal point to identify who is doing work in a particular rare disease entity. Currently, families can only guess where they might go for help. It would be much better to have a resource at hand that could elucidate critically needed care and research information. Currently, the ORD has a budget of $1.6 million. I implore you to make this office what it needs to be by increasing this budget to at least $4.8 million.

Both scientific and clinical research is needed to improve our understanding of and treatment for raredisorders. It is important to remember that although a condition being investigated may be rare, successful research may have tremendous impact on a much larger number of individuals. For example, the NIDR sponsored a program that placed dental implants into the jaws of 50 individuals affected by ED. Not only did the project underscore the value of implants in a dentureless adult, it also supported the procedure for use in children.

It is important to note that the research at the National Institute for Dental Research has had an additional benefit. The NFED, thanks to cooperation from several outstanding dental schools, their staffs, and Implant Innovations, Inc., and NovoBiocare, a manufacturer of implant components, offers special implant programs to the dental schools association with Southern Illinois University, the University of North Carolina, and the University of Washington. The private sector has now picked up that which was begun in the public sector.

Although the bulk of my testimony is devoted to funding for the NIH the value of the general dentistry residency program is worthy of comment. The program not only improves the depth of training for dentists but also enables individuals needing specialized care to identify practitioners and programs where help may be available. Diet, speech, self-esteem, business success and employment are all impacted by the condition of the mouth. We support the position of the American Association of Dental Schools for funding of at least $4 million with a caveat that additional funds be added should the reauthorization bill include pediatric dentist training as I hope it will.

One last concern that I would like to share with you is inadequate funding to get investigators to begin their research as follows: during their fellowship projects may begin for which financial support is lost at the end of the fellowship. There needs to be a system whereby fellowships involving rare disorders can be expanded with adequate financial support when warranted. My list could go on and on.

Mr. Chairman, I know that you are well aware of the anguish of parents whose children are affected by rare conditions. My hope is that you will spearhead an effort to increase the role and budget of Office of Rare Diseases, and like everyone else who has been here, we applaud and thank you for all of your efforts on behalf of biomedical research.

Mr. Porter. Ms. Richter, thank you. We rarely hear someone say leave these decisions to science, because obviously one wants to advocate that their concerns are more important than

any other, but I would like to reinforce what you've said. All of us have strong opinions that we want factored into this process, and we express them through the report; we express them to the institute directors that come before us to testify; to Dr. Varmus directly, but in the end, we know that their judgment, the judgment of science, is a better judgment than the judgment of politics. We also realize there's politics in science, but I think anyone who has ever dealt with NIH always comes away as we do with a feeling that they listened; that they're fair; that they try to respond to people's concerns just as much as we do, and I think your message that, in the end, that's the process that we have to trust, and we have to simply give them the resources they need to do these things, and they will follow the best opportunities and the greatest needs and will listen to all of us. They'll listen to you, and they'll listen to us too, but we can never tell them, ``We direct you to do this,'' because then we're stepping on a jurisdiction that really isn't ours. We have the authority but not the jurisdiction.

Ms. Richter. I appreciate your understanding of that. I think it's something that I've come to only after years of being involved with the institutes both as a member a research advisory council and as a lay advocate. I appreciate your thoughts.

Mr. Porter. Thank you for your testimony.

[The prepared statement of Mary Kaye Richter follows:]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 801 - 810--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

ELLEN GLESBY COHEN, LYMPHOMA RESEARCH FOUNDATION OF AMERICA

Mr. Porter. Ellen Glesby Cohen, president and founder of the Lymphoma Research Foundation of America, testifying in behalf of the foundation.

Ms. Cohen. Good afternoon, Chairman Porter. My name is Ellen Cohen. I'm honored to be here today as founder and president of the Lymphoma Research Foundation of America, the Nation's largest organization dedicated to providing comprehensive information and support to lymphoma patients, their family and friends.

The Lymphoma Research Foundation of America also finances research into better and safer treatments for the third most rapidly rising cancer in the U.S. Although this disease claims more victims everyday and although understanding lymphoma could shed light on many other diseases, funding for lymphoma research amounts to just 2 percent of the National Cancer Institute's budget. We are looking to this subcommittee for the

hope and strength we need to persevere in our battle against this killer called lymphoma.

I'd like to share with you the story of my own battle with lymphoma as a way of illustrating just how crucial your work is. In 1987, my husband, Mitch, and I were the proud parents of an 18-month-old daughter, and we were waiting for our second child to be born. My husband's internal medicine practice was growing, and I was a busy T.V. commercial producer. Life was good except for the nagging tiredness I constantly feel. It also seemed that I got the flu or a cold every time I turned around. The lymph nodes in my neck kept swelling up, and my feet were very swollen. I went to the doctor but blood tests did not reveal anything suspicious.

My son, Josh, was born in October of 1988, and when I didn't bounce back from the birth and lumps kept growing on my neck, my husband sent me to an oncologist. She took one look at me and sent me straight to the hospital for a biopsy. A week later, we had an answer, but it wasn't the answer we wanted to hear. I had lymphoma, cancer of the lymph system, and it's incurable.

At the time, I wasn't even 40 years old. My doctor said to go on with my life. I was sick they said, but not sick enough to receive aggressive treatment at the time. But how do you act like nothing is happening to your family when cancer is lurking in your body?

Somehow, we made it through a year and a half. Eventually, I developed a 99 percent obstruction in my nasal pharynx, and I could hardly breathe. It came time for me to experience high-dose chemotherapy, and within days of that first treatment I was back in the hospital with a collapsed immune system. I had just five white blood cells left in my body. I didn't even have the strength to hug my children.

Eventually, the therapy did its job, but it wasn't medicine that gave me the will to fight, it was thestatistics behind this devastating illness. Lymphoid malignancies strike upwards of 85,000 Americans each year, and there is a 50 percent mortality rate. It is one of the most rapidly rising cancers in America today. Yet it seems that no one knows much about it. Even the scientific community is not sure what causes it, and at the time of my diagnosis there was no national organization funding research, educating the public, or supporting patients.

I had to do something, so I picked up the telephone and began calling everyone I knew. Each phone call led me to someone else: another doctor, another patient. Those conversations convinced me that I could start a non-profit organization that could make a difference, not just for myself but for the health of all Americans.

You see this disease knows no boundaries. Anyone can get it: a former first lady, a former senator, a professional hockey player, two of my neighbors. Approximately 600,000 Americans today are living with lymphoid malignancies. Some days it feels like I hear from all of them at once. I have to fight back the tears when I hear from a 23-year old graduate student from Illinois who tells me that she's relapsing after only a year of remission, and she's running out of safe and effective treatment options.

I started the foundation to raise money, but what is

priceless is the hope we have raised. We started the first lymphoma-specific support groups, internet site, patient help line, and quarterly newsletter. To date, the Lymphoma Research Foundation of America has funded 43 lymphoma research projects totaling more than $1.25 million at top cancer centers and universities across the country, however, lymphoma is a growing, serious public health problem.

Recent research shows that there are links between understanding the causes of lymphoma and understanding the causes of many other cancers including leukemia, lung, breast, and prostate. We are finding that there are several crucial scientific issues that require immediate attention such as the links between viruses and bacteria with lymphoma and the role of environmental toxins in triggering lymphoma.

The Lymphoma Research Foundation of America has achieved a lot, but this disease is formidable. It is a formidable opponent, and it strikes us in the very prime of our lives. Of all cancers, lymphoma is the fourth largest killer of men ages 25 to 60 and the fifth largest killer of women in the same age group. Sixty percent of all childhood malignancies are lymphoma related diseases.

The good news is that scientists believe that lymphoma research will unlock the secrets to many other cancers. That is why for Fiscal Year 1999, Mr. Chairman, we seek the subcommittee's continued support in funding the research essential to finding better treatments and a cure for lymphoma. In furtherance of this goal, we request that Congress increase appropriations for the National Institutes of Health, and, as a first step, the Lymphoma Research Foundation of America joins the ad hoc group along with the other research organizations in supporting a 15 percent increase for the NIH Fiscal Year 1999. Further, we support doubling of the NIH budget in five years.

For the National Cancer Institute, the foundation supports the institute Fiscal Year 1999 bypass budget request of $3.191 billion. The foundation requests that this subcommittee include in its Fiscal Year 1999 committee report language specifically calling for increased appropriations for lymphoma research; use of all available mechanisms for expanding the scope of research including convening a scientific workshop to examine the current state of lymphoma research and exploring opportunities for additional study; use of program announcements and requests for applications on lymphoma-specific research topics, and research into potential environmental and other factors responsible for lymphoma.

Thank you very much for the opportunity to tell my story, and than you for your hard work and your consideration.

Mr. Porter. Ms. Cohen, I've lost, just this past year, one of my close friends--a man I went to college with years ago--to lymphoma, so I realize, I think, a little bit about what you're telling us, and we will, as I said before, we're going to do our best to meet that goal. If we don't get the resources to do it this year, we're going to fight to get them next year, but we're going to stay with it.

Ms. Cohen. And we'll do all we can too.

Mr. Porter. Absolutely. Thank you.

Ms. Cohen. Thank you.

[The prepared statement of Ellen Glesby Cohen follows:]

[Pages 814 - 821--The official Committee record contains additional material here.]

Mr. Porter. Now, let me say that we have reached four o'clock which is the time we intend to finish. We are just a little more than half way through our witness list. There are nine witnesses left. I have appointments waiting back in the office as well. I apologize to all of our witnesses for being this far behind. Unfortunately, we had a very long morning that lasted until one o'clock, and I had appointments between one and two that got us even further behind. We're going to take a short break at this point, and then come back, and we're going to try to be--I'll try to be as efficient as I can in listening to each of the remaining nine witnesses and not delay you any longer than we already have.

The subcommittee will stand in recess for five minutes.

[Recess.]

Thursday, January 29, 1998.

WITNESS

RITA CARTY, TRI-COUNCIL FOR NURSING

Mr. Porter. Rita Carty, DNSc, RN, dean of the College of Nursing and Health Science at George Mason University in Fairfax, Virginia, testifying in behalf of the Tri-Council for Nursing. Ms. Cary, welcome.

Ms. Carty. Thank you, Chairman Porter and members of the subcommittee; good afternoon. I am Rita Carty, dean of the College of Nursing and Health Science at George Mason University in Fairfax, Virginia. This testimony is abbreviated from my full statement, and I request the full statement be printed in the record.

I present the Fiscal Year 1999 funding recommendations for nursing education and research of the Tri-Council for Nursing. The Tri-Council is composed of four major nursing organizations: the American Association of Colleges and Nursing, the American Nurses Association, the American Organization of Nurse Executives, and the National League for Nursing.

First, I want to thank you, Mr. Chairman, and the members of this subcommittee for the Fiscal Year 1998 funding levels for the programs critical to nursing education and research: The Nurse Education Act, scholarships for disadvantaged students, the National Institute of Nursing Research at NIH, the Agency for Health Care Policy and Research, the National Health Service Core Scholarship and Loan Program, and others. We can assure you that these needed funds will be spent to improve the public health.

Last year, the President's Fiscal Year 1998 budget made adequate funding of these vital programs a real challenge for us all. We hope that the numbers will be much better in the administration's Fiscal Year 1999 proposal.

For Fiscal Year 1999, for the NEA, the Tri-Council respectively requests an increase of 8 percent over Fiscal Year 1998 to a level of $70.92 million. For SDS, we seek an increase also of 8 percent to $20.235 million. For NINR, we recommend a 15 percent increase to $73.136 million. For ACPAR, we ask an increase of 6 percent of $155.221 million. For the National Health Service Core Scholarship and Loan Repayment Program, we seek an increase over Fiscal Year 1998 of 5 percent to $82.074 million. Please let me explain our reasons.

In terms of the Nurse Education Act, NEA is a key source of Federal financial support for nursing education programs and nursing students. The NEA primarily seeks to encourage preparation of advanced practice nurses for underserved populations. The fact is that the NEA is the sole source of Federal support for advanced practice nursing education. The APNs include nurse practitioners, certified nurse midwives, clinical nurse specialists, and certified registered nurse anesthetists. These well-trained professionals are highly sought after by hospitals, community-based health care centers, and other providers. The NEA funds programs to educate APNs and future nursing faculty; offers modest stipends to masters and doctoral students, and seeks to help disadvantaged students obtain nursing education.

The NEA encourages linking training to the delivery of primary care to underserved populations, assisting continual education in rural areas and encourages schools to increase enrollment. It offers repayments of academic loans for nurses that agree to practice of nurse shortage such as public hospitals, community health centers, American Indian facilities, and public health service facilities.

The NEA fosters programs to prepare nurses to meet the health care system's need for nursing professional to address sicker patients in tertiary care sites; people living longer with chronic conditions, and often complex health care needs of an increasingly elderly population. NEA programs have incentives for schools to train for work with underserved populations. NEA funds serve as Federal leverage to reward schools and students for meeting work force needs of our rapidly evolving health care system. Whatever that system ultimately becomes, nursing professionals will continue to provide needed health care services.

More specifically, NEA assisted the development and expansion of 60 percent of current educational programspreparing nurse practitioners for primary care. Ninety-five percent of NP graduates work in primary care, and 44 percent of NPs have at least 25 percent Medicaid patients in their caseloads. NEA supported about half of the doctorly-prepared nursing faculty teaching today, and I'm a product of funding of NEA.

NEA provided stipends in 1997 to almost 37 percent, or over 12,000 full-time graduate nursing students and 267 grants totaling $15.6 million. The NEA significantly increased the number and retention of minority nursing students and faculty boosting the number of minority nursing graduates by 25 percent over the past 5 years. NEA funds facilitated development and or operation of 50 percent of currently operating nurse-managed health care centers that serve diverse populations of minorities, elderly, schools, housing complexes, and homeless

people. It supported 80 percent of certified nurse mid-wifery programs and 89 percent of certified midwives serve low-income women. It helped train certified registered nurse anesthetists, and these are the people who are the sole providers of anesthesia services in 70 percent of our rural hospitals.

With an eye to the future, NEA sponsored and collaborated on research on nursing work force to help maintain a relevant educational focus and production level. An NEA project at ACT, the Loyola University of Chicago's School of Nursing, prepares primary health care nurse practitioners in women's health to work with women in high-risk populations on mental health, chronic diseases, violence, early detection of cancer, access to care, and other issues.

Another NEA grant seeks to increase the number of disadvantaged and minority nursing graduates at Prairie View A&M University in Texas. Several NEA programs use special mentoring and academic assistance to help nursing students complete their courses of study and then return to underserved areas to practice nursing.

At the Marquette University College of Nursing in Wisconsin, NEA funds support a pediatric nurse practitioner clinical specialist program that will graduate APNs capable of providing high quality, cost-effective primary and preventive care to children living in poverty.

The NEA supports a new family nurse practitioner program at the University of Arkansas College of Nursing and has generated 38 graduates, half of whom practice in medically underserved areas.

Mr. Porter. Ms. Carty, I know you have several pages left there. We're not going to be able to hear it. Can you reach your conclusion?

Ms. Carty. Yes, sir. In conclusion, the Tri-Council wants to thank the subcommittee for its support of nursing education and research in the past, and we hope that you will continue to support nursing education and research in the future, and I would answer any questions.

Mr. Porter. We will, we definitely will. Thank you for your testimony.

Ms. Carty. Thank you.

[The prepared statement of Rita Carty follows:]

[Pages 825 - 831--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

DR. JOHN H. LYNCH, AMERICAN UROLOGICAL ASSOCIATION

Mr. Porter. John H. Lynch, M.D., staff director of the Division of Urology at Georgetown University Medical Center in Washington, D.C., representing the American Urological Association. Dr. Lynch.

Mr. Lynch. Mr. Chairman, I'm Dr. John Lynch, chief of the Division of Urology at Georgetown University Medical Center. I

had previously had the privilege of testifying before this subcommittee several years ago on behalf of prostate cancer research funding. That was immediately after the death of someone who was a patient of mine; who I became friendly with over the years that I took care of him, and who was well known to this subcommittee, Phil V. O'Contee.

I am pleased today to have the opportunity to present the recommendations of the American Urological Association for Fiscal Year 1999 funding for urology research at the National Institute of Diabetes and Digestive and Kidney Diseases and the National Cancer Institute. I will summarize my written statement that has been submitted for the record.

On behalf of the AUA, I want to thank the Congress, this subcommittee, and especially you, Mr. Chairman, for your strong support of NIH and the CDC and for your continuing interest in neurologic science. The increase in Fiscal Year 1998 funding for these key health agencies is very welcome and is deeply appreciated by the entire research community. The recognition by Congress that the activities of the agencies must remain critical priorities for the Federal Government is important for all of our citizens.

This morning, representatives of the AUA attended a White House briefing with other cancer research advocates, and heard Vice President Gore announce plans for a major increase in spending for cancer research at the NIH. We welcome this commitment and urge Congress to work with the administration to support and enhance these initiatives. The AUA will work closely with this subcommittee and the administration to achieve this goal. We will take this message to the congressional budget committees and the leadership of the Appropriations Committee to make sure that the dollars will actually be to your subcommittee to fund new cancer research.

It is our hope that the impact of urologic cancer will finally be fully recognized and a generous share of these funds will be quickly available to catapult of our understanding of prostate, bladder, and kidney cancers. These cancers are a significant public health problem as 50 percent of cancers in men are urologic in origin. The research needs and opportunities are great in this area, and funding levels have not kept pace. A significant infusion of funds will greatly accelerate work in this area, because we would be able to capture the developments in other basic science fields and apply them to the particular questions of urologic cancers.

I would like to report on the state of funding for basic urologic science at NIDDK. Despite the generous increase provided to NIDDK this fiscal year, the institute has chosen to restrict urology to 3 percent growth. Because of previous funding decisions at NIDDK, the urology program has actually lost ground. The AUA is very concerned by this situation. We have recently been assured that future increases will at least parallel the growth in the institute's budget. This is encouraging, but we ask this subcommittee's help to make sure that the commitment can become reality.

This subcommittee had called on NIDDK to begin work on a women's urological program, recognizing the important impact these diseases have on women's health and the paucity of research activity in this area. The recent conference explored

the many clinical and scientific issues, and we trust that NIDDK will use this experience to build a strong initiative in the next year. The AUA hopes very much that the subcommittee will review this situation carefully with the NIH when the agency's leadership presents testimony.

We believe that many of the problems with urology research are due to the lack of focus for urology at NIH. Until recently, grant applications in urology were being sent to as many as nine institutes with possible review by any of over 20 study sections, none of which had any expertise in urology. This subcommittee has addressed this issue in the past, and I would like to bring you up to date on some of the recent developments.

NIH has created a urology special emphasis panel to review grant applications. The AUA is encouraged by the early progress of this panel. However, we continue to recommend the concentration of urology research into fewer institutes as well as the reduction in the number of study sections reviewing urology applications. These remaining study sections should be expanded to include additional urologic scientists to ensure that the necessary expertise is there to have adequate peer-review of the application.

Recently, NIH assured us that this reconfiguration can be achieved. We believe that the changes can be made within the year, and we will look to you for counsel as we proceed in our discussions with NIH.

Mr. Chairman, that completes my testimony. I would be glad to answer any questions.

Mr. Porter. Dr. Lynch, thank you very much. We do share your concern, and we will work with you on that. Thank you very much.

Dr. Lynch. Thank you very much.

Mr. Porter. Thank you very much for testifying.

[The prepared statement of John Lynch, M.D., follows:]

[Pages 834 - 844--The official Committee record contains additional material here.]

Thursday, January 29, 1997.

WITNESS

RONNIE B. LANCASTER, ASSOCIATION OF MINORITY HEALTH PROFESSIONS SCHOOLS

Mr. Porter. Ronnie B. Lancaster, MD, JD, President of the Association of Minority Health Professions Schools, testifying on behalf of the association. Mr. Lancaster?

Mr. Lancaster. Thank you, Mr. Chairman, and good afternoon.

I am Ronnie B. Lancaster, Senior Vice President for Health and Social Policy at the Morehouse School of Medicine, but today appear as President of the Association of the Minority Health Professions Schools.

Mr. Chairman, these schools are responsible for having trained fully over 50 percent of the Nation's black physicians and dentists and 75 percent of the Nation's black veterinarians.

Mr. Chairman, I would like to make three points in summary of my testimony. However, before beginning, I would like to first thank you for your leadership and thank this subcommittee for their record of support of those programs which have allowed our institutions to train these individuals who serve in underserved communities.

I'd also like to say at this time, Mr. Chairman, that I consider it a point of particular privilege to thank this subcommittee for the work of Congressman Louis Stokes. Congressman Stokes has not only well represented the citizens of Cleveland, the residents of Ohio, citizens of this Nation, but is clearly a hero in representing the interests of poor and minority citizens in this country and helping to ensure adequate access to healthcare services.

Now, Mr. Chairman, three brief points. First, I would like to express our appreciation for your support and the support of the subcommittee for the Title 3 Program, Title 3 of the Higher Education Act administered by United States Department of Education. As you know, Mr. Chairman, this is a program that provides very important support to enable our institutions to strengthen development offices, libraries, and important infrastructure such as information-technology programs. This is an important program, Mr. Chairman, and, without exaggeration, represents the difference between keeping our doors open in our institutions.

Second, as the subcommittee knows, managed care has transformed and continues to rapidly transform the healthcare landscape. It has caused many changes around the country and has important implications for all medical schools and their faculty-practice programs, and it is no exception for the faculty-practice programs at the institutions that I represent. As a result of the support of several programs at Health and Human Services, our institutions are in the process of assessing the opportunities and the challenges that our plans face in this new managed care environment. Mr. Chairman, you should know that the average medical schoolin this country receives fully somewhere between 30 and 60 percent of its operating revenues from their faculty-practice plans. Unfortunately, the faculty-practice plans at our institutions contribute between 0 to 5 percent. And so clearly there is much work to do, and we ask the subcommittee's support for additional funding of $1.5 million for the Office of Minority Health to assist us in continuing and completing this analysis.

Finally, Mr. Chairman, we are all proud of the caliber of research being carried out under the direction of the National Institutes of Health. Our institutions are strong supporters of additional funding for NIH. However, as you may know, participation among African-American researchers and also Hispanic researchers is quite modest. In 1993, the Chronicle of Higher Education reported that African-American researchers received less than four-tenths of 1 percent of funding from NIH and Hispanic researchers received less than 1.6 percent research dollars rewarded competitively from NIH.

As we contemplate substantial increases in the NIH budget, I believe that we have an unprecedented opportunity to help ensure the full participation of competent researchers from these communities which represent the most at risk and sickest

among us. We recommend, Mr. Chairman, the establishment of a research endowment program to assist those institutions which have both a mission and a record of caring for poor and minority citizens, and now, where those institutions participate now only modestly in NIH funding, to assist them in building research programs to help ensure the fuller participation of researchers conducting scientific inquiry into those diseases which disportionately affect poor and minority citizens.

Mr. Chairman, it has been a pleasure and an honor to appear before you today. I appreciate the opportunity.

Mr. Porter. Ronnie, I probably ought to explain that Ronnie and I know each other very well. Ronnie is a very good friend of my son David. So I usually don't call the witnesses by their first names

Ronnie, the words that you said about Louis Stokes were so absolutely true. And learning of his planned retirement has been a great blow to all of us. I don't know how we'll do without him. He's been on this subcommittee and an active and strong leader of this subcommittee for longer than I have been in Congress. I haven't had a chance to express that publicly and to Louis, but we're going to miss him a great deal. As you know, he, in the last year of his service in Congress, will continue to provide the kind of leadership and representation that will help us to address the issues that you have raised in your testimony.

So, thank you for coming to testify. I'll pass along your good words about Louis to him. And it is really good to see you.

Mr. Lancaster. Thank you, Mr. Chairman.

[The prepared statement of Ronnie Lancaster follows:]

[Pages 847 - 853--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESSES

J.E. CHAVEZ PAISLEY
STEVEN C. MALLORY, NATIONAL COALITION FOR HEART AND STROKE RESEARCH

Mr. Porter. J.E. Chavez Paisley, Volunteer Liaison, Stroke Connection, Incorporated, accompanied by Steven C. Mallory, Stroke Support Web Site Coordinator, testifying on behalf of the National Coalition for Heart and Stroke Research. Thank you both for being here.

Ms. Paisley. Hello. I am J.E. Chavez Paisley of Pennsylvania. I represent the National Coalition of Heart and Stroke Research. Our coalition's 14 organizations represent over five million volunteers and members nationally.

I'll read a message for you written by Marylander, Steven Mallory.

``I signed up to serve my country at 18, right into the infantry. I got married when I was 19; honorable discharge at 22; started my college education part-time at night; worked

full-time during the day. The two kids were born. We bought a house. I graduated in 1992. Things were going great.

June 20, 1994, I was in France. A 36-year old FAA representative heading up a team of Martin Marietta aerospace engineers on the airbus thrust reverser. My whole life, including that of my family's immediately changed. I had a brain-stem stroke.

The area that controls motor skills was severely damaged. Nine out of the twelve cranial nerves that control the body don't work anymore. Breathing, eye movement, bowel and bladder control, and paralysis from the nose down.

Now, my life is completely different. I regained some movement. I must rely on my wheelchair 100 percent. My speech was gone. Today, I have a lift in my mouth and teflon inserts on my vocal cords to help me speak. Cognitively, I'm not damaged.

My life is only what I and my family make of it. I cannot do what I used to do: comb my hair, brush my teeth, scratch an itch or blow my nose. They are done for me. I am completely dependent.

Internet is my link to the outside world. I have made many stroke friends. The most frequently asked question is, ``Why? Why me?'' Will my children have to ask that question?

Research can provide the answers for these questions. I came here to ask you to increase the funding for stroke research. Thank you.''

Steven is one of the 4 million stroke survivors in our country, 4 million. There are almost 60 million Americans who have cardiovascular disease. Cardiovascular disease or stroke will hit one out of every five of your constituents. You who are day-in and day-out held responsible for our country's bottomline must know that our 1998 epidemic will cost our country $274 billion in medical expenses and lost productivity.

At the age of 41, I was hit by a massive cerebral hemorrhage, four aneurysms and a stroke. My heart flatlined twice, but it was restarted by a defibrillator. I was partially paralyzed and totally blind. I crawled on all fours. Two brain surgeries later, two eye surgeries, and three quarters of a million dollars later, I realized that I was one of the lucky ones, the rare ones. My damage occurred in an area of the brain that allowed for ample recovery.

Heart disease is our Nation's number one killer for both men and women. And stroke is our number three killer and our number one disabler. It is a silent epidemic. Survivors, like Steven, are not marching, not pacing outside your office, not waiting until you get off--take--not waiting for you to take him off hold while you finish your report. No, they have been silent. You may have the time to consider these testimonies, but the person whose brain is attacked 53 seconds from now won't.

The coalition knows the difficult choices that you have had to make in the past few years to sustain this Nation's commitment to medical research and the NIH. We thank you, Chairman Porter, and the subcommittee for its strong support for medical research funding. The coalition supports a 15 percent increase in funding for the NIH in the Fiscal Year 1999 as the first step to doubling the NIH budget over the next five

years. Sixty million Americans who suffer with cardiovascular disease and the National Coalition for Heart and Stroke Research is also asking you to provide a 15 percent increase in funding for heart and stroke research for NHLDI and NINDS. You will save our country money and hurt. After all, what good is a country without a heart or a brain.

We thank you very much for your time.

Mr. Porter. Ms. Paisley and Mr. Mallory, I say this often, but all of us who are members of this subcommittee don't consider these matters in a vacuum because all of our families have been touched. My mother died of congestive heart failure after a series of strokes. My father died of a massive heart attack at a relatively young age. They touch every family. All I can say is that we are going to do the very best that we possibly can to reach those goals, and nothing, I think, is of higher priority than doing so. So, we're going to do everything that we possibly can.

Ms. Paisley. Chairman Porter, I think that probably one of the problems is that most people can see stroke and heart attack as just a senior's problem. And there are infants, there are people who are 36 years old who are getting it.

Mr. Porter. Oh, absolutely.

Ms. Paisley. Thank you so very much.

Mr. Porter. Thank you.

[The prepared statements of J.E. Chavez Paisley and Steven Mallory follows:]

[Pages 856 - 868--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

SHIRLEY COLETTI, NATIONAL COALITION OF STATE ALCOHOL AND DRUG TREATMENT AND PREVENTION ASSOCIATIONS

Mr. Porter. Our next witness is Shirley Coletti, DHL, President of Operation Par, Incorporated testifying on behalf of the National Coalition of State Alcohol and Drug Treatment, Prevent Associations and Legal Action Center.

Ms. Coletti.

Ms. Coletti. I thank the chairman.

I am Shirley Coletti, and I'm very sorry that Mr. Young and Mr. Miller aren't here today because Mr. Young has literally saved our program time after time and has been one of the great supporters. And of course, we serve many of Congressman Miller's constituents.

Mr. Porter. Ms. Coletti, Mr. Miller was here.

Ms. Coletti. I know.

Mr. Porter. I'm afraid I'm well over our time limit.

Ms. Coletti. I realize that.

Mr. Porter. Mr. Young, because he is the chairman of a major other subcommittee, he doesn't usually attend our hearings. He is just too busy.

Ms. Coletti. I realize that. We've been in touch with his

office.

Mr. Porter. We excuse him. I hope you will also.

[Laughter.]

Ms. Coletti. As you said earlier, I am representing the National Coalition of State Alcohol and Drug Treatment Programs and Prevention Associations as well as the Legal Action Center.

Through Federal funds and other funds, the programs that I'm representing provide services to addicted parents and pregnant women who want better futures for their children; addicted individuals in the criminal-justice system; and those who can move to a sober and a crime-free life; and millions of children and adults at risk for developing alcohol and drug problems.

Thank you, Mr. Chairman and the subcommittee, for last year's increases in alcohol and drug treatment and prevention research programs, and thank you especially for refusing to cut treatment dollars for alcohol and drug programs. Providing strong support for alcohol and drug treatment, prevention, and research is imperative to maintain and to improve the health and well-being of our country. These programs effectively decrease alcohol and drug use, crime rate, healthcare costs, AIDS, and welfare dependents.

I understand, as you were talking earlier today, about the need for results-driven programs, and I think that this field is becoming very cognizant of the importance of making sure of outcome results being available to--in order to really justify the expenditures that are requested.

The programs in Florida and around the country such as Par have been leaders in developing effective programs for women, for youth, and other underserved populations. With the help of Congressman Young last year and the year before, and with your committee, programs like Par Village, which is a residential, actual village which allows mothers who are suffering drug dependence to have at least two of their children in residence with them to go through residential treatment with at least an 80 percent success rate and a very low recidivism rate. So it is with those kinds of programs that we feel we are really making a major contribution. But on any given day, just in the State of Florida, there are over 1,400 individuals and families that are still in need of substance-abuse treatment services such as I am representing today. These people really represent just a small portion of the number of people that are in need.

As the States implement their welfare-reform programs, the demand for substance-abuse services will increase, especially for women with children. In most of our research, we find that at least 16 to 20 percent of individuals on welfare have alcohol and drug dependency. It is imperative that they have sufficient drug treatment and alcohol treatment if, in fact, we are really going to be successful with our welfare reform issues.

Robert Rector, the welfare expert at the Heritage Foundation, reported in the September and October issue of the Intellectual Ammunition that drug treatment programs improve job training readiness. Clearly, the availability ofalcohol and drug programs and prevention services must increase if we are going to be successful.

I would like to make some recommendations for providers to

supply the essential services in our State and throughout the Nation. We need your continued support. We urge Congress to adopt the following increases for Fiscal Year 1999 funding for alcohol and drug treatment, prevention and research programs under the Substance Abuse Mental Health and Administration, SAMHA, the Department of Education, and the National Institutes of Health. These are wise investments that will provide desperately needed services for communities across the country. $1.564 billion in the substance abuse prevention and treatment block grant represents a 15 percent increase over Fiscal Year 1998 including the $50 million appropriated for the contract with the American Advancement Act, $180 million for the Center for Substance Abuse Treatment, CESAT and the Center for Substance Abuse Prevention, CESAP and the horrible name of knowledge development and application projects--I don't think any of us like that. Let me just quickly tell you that this is not the time to be cutting back on spending for those knowledge development and application projects. The congressional support for increasing drug abuse research over the past ten years has produced an enormous base of knowledge regarding the treatment. With that base of knowledge, and with these knowledge development application programs that are going on all over the country, for the first time, I, who have been in this for 28 years, can begin to see the coming together and really the effective use of knowledge development after research-based programs.

I thank you for your time. I know that today is of timeless goings. So, any questions I would be happy to answer.

Mr. Porter. Ms. Coletti, thank you very much. I agree with you, that is a strange name.

Ms. Coletti. It's awful.

Mr. Porter. You can work on that.

Ms. Coletti. I'm trying very hard.

Mr. Porter. Thank you again. I would imagine that it is fair to say that almost every family in the United States has been touched by problems with alcohol or drugs and I think that we all realize the importance of it and what it costs our society, not just our families, but our whole society.

Ms. Coletti. It's devastating. I started 28 years ago because I had a daughter that I discovered at 15 years of age was experimenting with drugs. That daughter is now a post-doctoral fellow student and under a National Institute of Drug Abuse Grant, and she is doing fantastic research in the area of perinatal addition. So, it does work.

Mr. Porter. It does work.

Ms. Coletti. Thank you.

Mr. Porter. Thank you so much.

[The prepared statement of Shirley Coletti follows:]

[Pages 872 - 885--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

CHARLES E. YOUNG, STATE COMMISSION FOR THE BLIND

Mr. Porter. Charles E. Young, Administrator, State Commission for the Blind, testifying on behalf of the Council of State Administrators of the Vocational Rehabilitation.

Mr. Young. Thank you, Mr. Chairman.

``What do you do for a living?'' is a common question upon introduction. Can you imagine not having a reply? For in employment is how we, as adults, define ourselves. Our occupations determine with whom we associate, where and how we live. Our jobs are a source of identity, self-worth and association. Yet a recent Harris poll indicated that two out of every three American adults with disabilities are unemployed. The same Harris poll concluded that to have a disability and be unable to attain employment is the true meaning of being quote, ``handicapped,'' in our society.

Clearly, we have yet to extend the American dream of inclusion and full participation in society to many citizens with disabilities. Without hope of employment or the training to live independently, disabled Americans are denied the opportunity to contribute to and fully experience our Nation's greatness.

Limited fiscal resources have so restricted the Nation's rehabilitation efforts that today State vocational rehabilitation agencies are able to serve only one in twenty eligible individuals with disabilities. While the United States annually spends in excess of $200 billion maintaining citizens with disabilities we allocate less than $2.5 billion on rehabilitation leading to employment.

Clearly by allocating more funds to vocational rehabilitation programs we can save hundreds of millions of dollars on maintenance. Simply put, vocational rehabilitation can be seen as a $2 billion response to a $200 billion problem. With adequate funding, State and Federal Government, in partnership with the consumers of rehabilitation services can create a climate in which Americans with severe disabilities will meet the challenge of becoming participating, contributing members of our society.

Approximately 200,000 such Americans with disabilities are annually placed into employment by our program. Our efforts to streamline the vocational rehabilitation process to be even more responsive were recently recognized by Vice President Al Gore through the presentation of the Hammer Award.

It is said that what good government does best is invest in the protective independence of its citizenry. Our rehabilitation programs place unprecedented faith in the abilities of disabled Americans by investing in their career choices. The Rehabilitation Act enables Americans with disabilities to become productive, independent citizens and contributors to their communities. In essence this is the best of what America has to offer.

On behalf of your partners in rehabilitation, we at the Council of State Administrators of Vocational Rehabilitation applaud the committee members for your efforts to date and request you to provide a Federal appropriation of not less than $3 billion for Fiscal Year 1999 for vocational rehabilitation programs. Together we can change what it means to be an

American with a disability and enable this population to respond with dignity to the central question, ``What do you do for a living?'' We could make vocation rehabilitation at least a $3 billion response to a $200 billion problem.

Thank you, Mr. Chairman.

Mr. Porter. Thank you very much, Mr. Young. We very much appreciate you coming and giving us your testimony. It is a very important subject for us to work on together. Thank you for your appearance.

[The prepared statement of Charles Young follows:]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 888 - 890--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

JULIE SELLERS, ASSOCIATION FOR PROFESSIONALS IN INFECTION CONTROL AND EPIDEMIOLOGY, INC.

Mr. Porter. Julie Sellers, registered nurse and Infection Control Coordinator for the Louisiana Health System representing the Association for Professionals in Infection Control and Epidemiology, Incorporated.

Ms. Sellers. Very good.

Mr. Porter. Ms. Sellers. Yes, very good, I got through that. [Laughter.]

Ms. Sellers. I'm here today to talk about some savings. I am here representing APIC which is the Association for Professionals in Infection Control and Epidemiology.

APIC is a non-profit organization representing nearly 12,000 individual infection control professionals who work in a variety of health care settings. APIC has long been a strong proponent of scientifically-based programs and policy designed to protect public health such as those of the Centers for Disease Control and Prevention.

We are extremely concerned, however, about regulation that is not science-based, is unnecessary and is costly to implement. Specifically, I'm speaking today in reference to OSHA's proposed rule to prevent tuberculosis exposure to health care workers.

OSHA issued its proposed rule in October. Since that time, APIC has been working with a broad-based coalition of health care providers to assess the true impact of this proposal. It is clear that this role will adversely impact facilities such as hospitals, nursing homes, clinics, and homeless shelters. It will be virtually ineffective in reducing health care worker exposure to TB.

OSHA's proposal has also incited the concern of the Small Business Administration's Office of Advocacy whose officials have significant concerns about the economic and technological

infeasibility of this proposal.

We health care providers in this country need Congressional support in opposing this rule. Chairman Porter, you and Congressman Wicker have graciously offered your support and have written to Secretary Herman directly to urge a halt to the rule's promulgation. OSHA's rationale for issuing a rule on preventing TB exposure to health care workers is fundamentally flawed. The entire proposal is based on the false premise that workers caring for known or suspected TB patients need additional protections above and beyond those already in place.

The real risk to health care workers is not in caring for identified TB patients. In these cases, the facilities would have already taken the proper precautions to guard against worker exposure as recommended by the CDC. The real risk is in caring for the patient who has TB but has not yet been diagnosed. In fact, if one looks at the factors contributing to employee exposure to TB, more than 75 percent of the time the source is an undiagnosed patient.

It can sometimes take days or even weeks to accurately diagnose a patient as having TB particularly if he or she is initially hospitalized for a different reason or has vague systems. During the time that elapses between admission and diagnosis, many health care workers may unwittingly be exposed to these patients. And unfortunately, these transmissions from undiagnosed patients are not readily preventable.

Indeed, OSHA admits in its own proposal that the undiagnosed TB cases are the primary factor in the transmission of TB to health care workers. Yet OSHA persists in proposing that those protections will eliminate the risk. The protections cannot possibly have an impact since they would never be put into place in situations where TB is not even suspected.

A blatant example of OSHA's inappropriate intervention is that in its suggestion for health care providers to combine task, limit the number of employees entering a TB-isolation room, and limit the time that they spend with their patient. Limiting access to care poses an ethical dilemma to health care facilities whose mission is to care for patients.

This particular proposal also begs the question, ``If OSHA believes that its proposed protections are effective in safeguarding against TB exposure, why, then would there be any need to minimize the time spent in the room with the patient?''

OSHA's formulation of this rule is in response to a resurgence of TB in the United States that began in 1989 but has been under control since 1992. In fact, the incidence of TB has now dropped to the lowest national level ever recorded.

The CDC issued revised guidelines for the prevention and control of 1994. These guidelines have been implemented as appropriate in a majority of United States' hospitals today. Their widespread acceptance is due to the fact that they are effective, scientifically sound, and flexible for application according to levels of risk.

In conclusion, APIC firmly believes that the CDC is far more knowledgeable than OSHA to handle TB prevention and control for both health care workers and consumers. The changing nature of infectious diseases makes it imperative that any guidelines be flexible and continuously updated. The current CDC guidelines provide us with this flexibility. A

static OSHA regulatory standard would not. There is no need to waste taxpayer dollars on a completely separate, OSHA regulatory structure to address TB.

We urge you to challenge OSHA's rationale behind this unnecessary regulation. This role will only place additional burdens on providers already facing decreasing governmentalreimbursements and increasing demands of managed care while providing no added protection for health care workers.

Facilities are currently regulated by a number of entities that provide sufficient oversight for protecting both patient and employee health.

We would recommend that there be better cooperation among agencies currently involved rather than the promulgation of new and overlapping regulations.

We thank you for your continued support on this issue, and I would be happy to answer any questions.

Mr. Porter. That was absolutely perfect.

Ms. Sellers. Thank you. [Laughter.]

Mr. Porter. This regulation is proposed? It has not been issued?

Ms. Sellers. It is only a draft. That is correct.

Mr. Porter. I know Mr. Wicker has been very concerned about that. We will work with him to address your concern and his.

I have a question. You are missing something. Where is your Louisiana accent?

Ms. Sellers. I work hard not to bring it up here.

Mr. Porter. You know, you are the second witness from Louisiana with no accent. Where is it? You have one at home and a different one here?

Ms. Sellers. Sometimes.

Mr. Porter. I see.

Well, we thank you very much for your testimony. We obviously agree, and we will work with Mr. Wicker and do our best to address that need through OSHA.

Ms. Sellers. We would appreciate it. Thank you.

Mr. Porter. Thank you.

[The prepared statement of Julie Sellers follows:]

[Pages 894 - 905--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

AUDREY HORNE, AUTISM SOCIETY OF AMERICA

Mr. Porter. Audrey Horne, President of the Autism Society of America testifying on behalf of the society. Ms. Horne.

Ms. Horne. Good afternoon, and thank you, Mr. Chairman. I come from South Carolina, and I don't bother to try to disguise it.

Mr. Porter. I guess not. [Laughter.]

Ms. Horne. There is no need to, and I work real hard to never lose it even after I've spent seven years working on Capitol Hill and associating with folks from all over the

country.

I do appreciate the opportunity to come before you on behalf of the Autism Society of America, and it is my pleasure to enter our testimony into these important deliberations.

You just said, my name is Audrey Horne. I am the President of the Autism Society of America which represents a membership of 24,000 fellow advocates.

I am the mother of a young son, who is an adult now, who has autism. He, in his unique needs, and those of my family, are the primary reasons for my decision to serve as a volunteer in the autism community. My husband and I, almost 30 years ago, had our lives come to a very abrupt and dramatic change from the birth of this child, our second. Our lives have been overshadowed ever since by that. But we have willingly accepted the challenge because we love him unconditionally as does his older sister and younger brother. We've been blessed by our own commitment and that help of others along the way. Remember now, if you will, that our son was born before you knew too much about autism and there was no mandatory education for the handicapped.

I want to thank you, Mr. Chairman, and for the others who serve on this important subcommittee, for the generous support that you have given to the needs of persons with autism in both the research and service arenas.

As you probably do know, autism is a serious, lifelong, neurological disorder affecting approximately one in seven hundred children. The annual cost of cure--or care, we're hoping to get to cure--for those with autism in this country has been estimated at over $13 billion. The vast majority of citizens with autism, even those with exceptional skills, need some type of support throughout their lifespans. Without effective training and support they would become more and more dependent on what was once referred to as welfare programs. Although there are promises in behavior and medical treatments to improve the quality of life for persons who have autism, at this time, we have to say that there is no known biological marker or cure for autism. That is, yet.

I'm asking, please, that you help us. Help us to help families who are physically, emotionally, and monetarily exhausted. Believe me, I know, because my husband and I are in the retirement part of our lives and a lot of other things would have made this a lot easier had we not had to expend so much on care. We did it without grudge, but it does affect your life.

And on behalf, too, of the hundreds of thousands of individuals who themselves have autism but who with the appropriate resources would be able to achieve more fulfilling, independent lives.

The ASA--the Autism Society of America--asks you please to approve significantly funding levels for the National Institutes of Health and to encourage them to utilize that increased funding for increased research not only into the biology of autism but to into research on treatments and services for individuals with autism.

Chairman Porter, I'm at the stage of my life, and so are many other parents, that we can't wait around for the cure. We've got to do something for those who are with us now.

In the past year, the National Institute of Childcare and Human Development and the National Institute on Deafness and other Communications Disorders have launched the largest, most far-reaching research project in autism history. As a result, ten collaborative programs on excellence in autism exist throughout this country of ours. And they are studying the causes of autism, brain structure, and function and howpersons with autism change as they age. Greatly increased funding for all of the institutes for research that looks for causes for autism, how it develops, what is needed to treat the disorder, and ultimately, we do hope it can be prevented and be cured. It is just desperately needed, sir.

This is an exciting time for parents of those who are impeded by this devastating disorder. At long last, we do have collaboration by research entities and sufficient funding appears to be at hand. Research findings suggest that there is--that the period of plasticity--when experience and intervention can change the brain--is much longer than was previously thought. And that certainly is encouraging to us. With valid treatments, we'll be able, we believe--and I believe this--and this would be reinforced by science--to improve what was once felt just to be irreversible damage. The NIH has mounted a campaign to understand the neuro-biology and genetics of autism.

Please continue your support of them and their efforts. They may be able to put the same energy and funding and to evaluate and improve treatments for citizens who already have autism. Help the NIH with this increased funding so that we may be able to work with them with full up coffers just as strong as the medical ones and they may have the means to use the same level of creativity and be able to do a top-notch job in the biology of autism.

There is a great deal that we don't know about autism. However, in the past, it has been the parents who knew more about it than anybody else because we live with it. Now, increasingly more and more the scientists and educators are learning a great deal more and can help us. There is a great deal that we don't know.

But the greater tragedy is that this country's children and adults who do have autism are not getting the best of what we already have. That should not be allowed to persist. You personally, Chairman Porter, and the people who work with you having previously shown your support for children--particularly those with special needs--your recent reauthorization of IDEA last session without any crippling amendments that would have eroded our children's rights was tangible evidence that dedication and wisdom. Thank you very much for your resistance for any efforts to undermine that. Aside from right now being the right thing to do, it is the smart thing. It is cost-effective in the long run.

Your continued support for the needs of our families will go a long way in abating our growing fears.

Parents age, and usually we know that parents die before their children do. Normally that is a part of the natural order of life. But one of the greatest fears that parents of adult have is dying and leaving and there being no one to do for our children. We are not asking for any benevolent government, of

course, to come in and do parent for us, but we do ask if you will please become partners with us in alleviating some of this pain and anxiety and help us to make improvements and to make cost-effective ones.

Our fervent prayer in the Autism Society of America is that none shall be left unserved or underserved, as we continue our advocacy.

I do most respectfully thank you for your time, your patience, and your understanding, and Chairman Porter, your compassion. Please be assured that the Autism Society of America spends as much as we possibly can within our limited resources to promote public awareness about our autism and to disseminate information that is accurate and up to date.

Thank you so much. It was worth the trip from South Carolina to come before this subcommittee and before a chairman whose activities I follow closely and admire so very much.

Mr. Porter. Well, Ms. Horne, you're very kind. This subcommittee really has been encouraging NIH to put autism at a much higher priority, and we are as glad as you are that they have chosen to do that in their new initiative.

Could I ask one question?

Ms. Horne. Surely. If I can answer it, I'll be glad to.

Mr. Porter. Well, tell me the circumstances of your son now.

Ms. Horne Thankfully----

Mr. Porter. He's 30 years old, did you say?

Ms. Horne. Yes, he'll be 30 next summer. We didn't have intervention as soon as we would have liked to have, but because of our own planning and the cooperation, I will say, the legislature and executive branches in South Carolina government to address this need, to make a long story short, he resides in Charleston, South Carolina now in a house with two other young men who have autism with staff around the clock. He works in the community. He is a wage-earner, and he's at just about the level now to start paying taxes. I know you'll be glad to hear that, and we all are, because we want him to have self-respect.

He's still got a long way to go. His communication disorders are still there, but he's enjoying a level of support and of living that has dignity in it, and does give his father and I more assurances as we age. We know that his brother and his sister will be his advocates, but they have families. Needless to say, we are grandparents also, as well as parents, and people have been so responsive. And that's one reason that I chose to serve in the first place, was, it may sound corny, Chairman Porter, but my husband and I decided that we wanted to take as many people along with us as we could, not to get it all just ourselves.

Mr. Porter. Well, we're delighted that you are taking that leadership role and that you've come all the way from South Carolina to testify before the subcommittee, and you brought your accent with you.

Ms. Horne. Yes, sir, and I plan to take it home tonight. [Laughter.]

Thank you.

Mr. Porter. I'm going to come down in a couple of weeks, and we have a conference I'm attending in Charleston.

Ms. Horne. Oh, well, I live quite near Charleston there. Where was your conference going to be, if I might ask?

Mr. Porter. I can't tell you the name of the--it's probably the nicest place, though, right in the historic area----

Ms. Horne. That's good.

Mr. Porter [continuing]. They said five or six blocks from the Battery or from the water at least.

Ms. Horne. We are having a quarterly board meeting. I'm flying back tonight, and Dr. Zaro, who came with me, is our executive director--so that I invited them to come to Charleston because I said they needed to be--everybody needs some time to go where the birth of civility was. [Laughter.]

That sounds chauvinistic, I know, but I am proud of our State, and we will be----

Mr. Porter. I can hardly tell.

Ms. Horne. Yes, you can hardly tell. We're meeting at the Mills House Hotel in the historic district.

Good luck, and I know that you've probably been to South Carolina before, but----

Mr. Porter. Yes, I have.

Ms. Horne [continuing]. I know that you will be most welcome there.

Mr. Porter. Well, thank you very much.

Ms. Horne. Thank you.

[The prepared statement of Audrey Horne follows:]

[Pages 910 - 916--The official Committee record contains additional material here.]

Thursday, January 29, 1998.

WITNESS

ROBERT STILLMAN, AMERICAN SOCIETY FOR REPRODUCTIVE MEDICINE

Mr. Porter. Robert Stillman, M.D., director, American Society for Reproductive Medicine, testifying in behalf of the Society. Dr. Stillman. You are last but not least.

Dr. Stillman. I appreciate it.

Mr. Porter. I'm sorry to keep you so long.

Dr. Stillman. No, I apologize for keeping you so long, but that is a very tough act to follow, but I'll see if I can keep my Illinois accent under abeyance.

Mr. Porter. Illinois accents do very well here as well. [Laughter.]

Dr. Stillman. I understand.

I'm medical director of the Shady Grove Fertility Centers here in Washington--I have come a very short way actually--and clinical professor of obstetrics and gynecology at Georgetown. I have the honor of serving on the board of directors of the American Society for Reproductive Medicine, the ASRM, whom I am representing here today.

ASRM is the Nation's leading professional organization for reproductive medicine. More than 9,000 members are its leading practitioners and investigators in the field. We're grateful for the opportunity, albeit late, keeping you all here today,

to appear before you and offer our views on the 1999 appropriations.

We have an interest in the number of the agencies before this committee in your purview, but I'll confine my comments here today to two: the National Institutes of Health and Centers for Disease Control and Prevention.

When discussing NIH, I must first begin by thanking the members of the committee and you for the strong bipartisan support for medical research over the last years, as you've heard all day today, with which we concur. Many of the Members of the Congress are calling for a doubling of the NIH budget, and we strongly concur with that and applaud the Members and the President for the stand in that.

As a beginning point to the doubling of the budget, we, too, as the other speakers here today, have recommended increasing the NIH budget for 15 percent for 1999. We are joined in this also by more than 200 members of the Ad Hoc Group of Medical Research Funding, a broad-based coalition of patient advocacy groups and professional organizations.

Specifically, most of the research in reproductive medicine, however, is funded through the NICHD, the National Institutes of Child Health and Human Development, and we also recommend that NICHD's appropriation be increased 15 percent for Fiscal Year 1999. Time will not allow me to discuss many of the fine programs, unless we'd like to stay much longer, but I do want to draw your attention to just two.

One is the contraceptive and infertility research centers. These centers have not received full authorized funding level, and we strongly encourage you to do that funding.

The second is a new one, and thanks to your leadership, NICHD is starting this year the women's reproductive health research career development programs. The program will allot $3 million from NICHD to top academic departments around the country to facilitate training and career development for young investigators in women's reproductive health issues. The program will both enhance reproductive research now and invest in tomorrow's investigators at a critical and vulnerable time in their careers, and at a time when many, many promising young lives are leaving academics and research due to the lack of funding.

Regarding the Centers for Disease Control and Prevention, in December, CDC, in conjunction with ASRM, in conjunction also with one of our affiliate societies, the Society for Assisted Reproductive Technology, SART, and RESOLVE, the national patient advocacy and fertility group, published the 1995 Assisted Reproductive Technology Success Rates Report. This publishing partnership was developed under the terms of the 1992 Fertility Clinic Success Rate and Certification Act, sponsored particularly by Representative Wyden. The report was, unfortunately, delayed from 1992 because of the lack of funding of the law, and finally it was enacted and supported, and the publication just came out. So thanks to that congressional leadership, consumers now have access to outcome data unlike that available in any other field of medicine.

By working together, government, patients, and providers have made it easier than ever for patients to be well-informed medical consumers. CDC has done an excellent job in

implementing the law. However, Congress did not make available additional funds for its implementation. This lack of funds has also caused the delay of implementation in the second part of the same act, the certification component, which is meant to develop standards for embryology laboratories, a very important issue.

In order to ensure that CDC can fully implement the terms of the law, ASRM recommends $7 million be specifically allocated by Congress to CDC for that purpose. Please invest in the future health of this country with the adequate funding of NIH and CDC programs, as you've supported to date.

I appreciate the opportunity to be here. We'd welcome any questions.

Mr. Porter. Dr. Stillman, let me see if I can understand this part about CDC and the implementation of the law. Say again why--I thought you said that we had not provided funding to implement the law.

Dr. Stillman. There was a long period of time when there was basically an unfunded mandate. There was the law, but not funding for it, and that was the difference between 1992and 1995. Currently, as I understand it, there is no funding for continuation of CDC's support for them to implement the law. So CDC is required to implement the provisions of the law, but doesn't have the funding for it or adequate funding for it, in particular, regarding embryology laboratories.

Mr. Porter. Let me look into this further and see why that is so. I was not aware. We have attempted to provide funding for whatever CDC asks for. Obviously, there's no line item for it----

Dr. Stillman. Right.

Mr. Porter [continuing]. But we have provided them substantial increases in recent years, and there should be funds for them to carry out that mandate. But let me check it.

Dr. Stillman. I appreciate it.

Mr. Porter. One other thing I'd like to say, and that is that the President's proposal is to increase to double-funding for research over 10 years and not 5. And we expect the President's budget to show about an 8 percent, 8.2 percent increase for NIH, which would reflect that doubling over 10 years. While this is very good news, because the President's budgets in the past have not been nearly that strong, it is not the same as the proposal of the Ad Hoc Committee, which is to double it over five years. So while I'm encouraged, I think it's fair to say we're going to have to work very hard and work with the Budget Committee to see if we can get the resources we need to raise that entire funding level higher, and that means we're going to have to impact the American people with the importance of this, in order to get that message back to Congress.

So thank you very much for coming in to testify. I again apologize for keeping you so late. We appreciate your informing us. I will look into this matter, particular matter, because I'm not aware of why that isn't being accomplished.

Dr. Stillman. Let me know if I can help.

Mr. Porter. Thank you.

Dr. Stillman. Thank you.

[The prepared statement of Robert Stillman, M.D., follows:]

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[Pages 920 - 925--The official Committee record contains additional material here.]

Mr. Porter. The subcommittee will stand in recess until 10:00 a.m. next Tuesday.

Tuesday, February 3, 1998.

WITNESS

ARTHUR J. AMMANN, M.D., AMERICAN FOUNDATION FOR AIDS RESEARCH

Mr. Porter. The subcommittee will come to order.

This is the fifth of nine sessions of two hours each with public witnesses that the subcommittee will conduct that puts us somewhere near 200 public witnesses. We're trying to accommodate as many as possible. We realize that not all can be accommodated. We have done our best to give everyone a chance to testify who's interested in doing so.

Because we have so many witnesses and so short a time, we have to be very insistent on the five minute limit. Up to this point, I have to say, the witnesses have been very good about that, and many obviously time their testimony so that it comes out right about the exact time.

The staff has gotten even tougher, because they now have a timing device. And if you hear the ringing of the little bell, you'll know that that's the five minutes. Carol Murphy is in charge of that this morning.

We welcome your testimony. The reason we have it early is that there are fewer chances for interruptions by votes on the floor. This year the President got his budget out in time so that you actually can if you want to comment on the numbers that you see the President has presented.

So we thank each one of you for coming this morning. We'll listen very intently to what you have to say.

Mr. Porter. We will begin our hearing this morning with Arthur J. Ammann, M.D., President of the American Foundation for AIDS Research, testifying in behalf of the Foundation. Dr. Ammann, why don't you take the center seat there, if you will, and proceed.

Dr. Ammann. Chairman Porter and members of the committee, thank you for inviting me to appear before you. I'm Dr. Ammann, President of the American Foundation of AIDS Research. My experience includes that of being a pediatrician. I worked at the University of California. I also worked for a biotechnology company called GENINTEX, and now I'm working with foundations.

In all those areas, I have seen the broad benefits of NIH-sponsored research. It has really been dramatic. Last year as I appeared before this committee on behalf of the HIV/AIDS community, we asked for an across the board increase in NIH funding. Your committee and Congress responded, for which we are thankful.

I think we are now witnessing one of the most dramatic increases in discovery in biomedical history. Today I urge you and your committee to keep this momentum going. AmFAR joins other advocates in biomedical research in asking for a 15 percent across the board increase for NIH.

I just returned from Chicago, Illinois. Going on right now is an HIV/AIDS committee in which I'm seeing the dramatic impact of NIH-supported research. We're really changing the face of this disease.

Many HIV infected individuals are living longer. They have now healthy and productive lives. In most cases we can prevent the accidental transmission of HIV. Very dramatically, we are at the point of eradicating HIV infection in newborn infants as it's transmitted from mothers to infants because of NIH-sponsored research.

But the discoveries made in HIV/AIDS are reaching out very broadly. They're touching the lives of thousands of individuals with other diseases as well. Before the HIV/AIDS epidemic, as I dealt with immuno-deficient patients, we had very few treatments available for opportunistic infections. Because of patients with HIV/AIDS and research, we now have multiple treatments that people can choose from to treat these very devastating diseases. These are people with cancer, kidney transplant, genetic disorders as well.

We also believe that HIV/AIDS has benefitted from the research done in other areas, cancer and neurology. For that reason, we feel there should not be a disease versus disease debate in terms of funding. Rather, the scientific community, armed with a strong NIH, adequate resources, the leadership of Dr. William Paul, that he has given to the OAR, we need another director, that needs to continue, and we're grateful for Dr. Harold Varmus, who has really shown strong leadership for the National Institutes of Health.

The question is, if we have been so successful in HIV/AIDS, do we need more support for HIV/AIDS. I would say emphatically, yes, we do. We have problems with AIDS. We've changed the mortality related to AIDS. We have fewer people with AIDS for the first time, but we have more HIV infected people. We have not cured a single patient with HIV infection.

So we have concerns that mean we have to do more research. We need better therapy, we need safer therapy, and less toxic therapy. We have to deal with the inevitable emergence of resistant virus. We need better therapy for opportunistic infection. We need therapy that's simpler, because we are seeing a discrepancy in the benefit from the research in disadvantaged populations.

I think we also need to recognize that we have to implement every ethical safe and effective measure that has been scientifically proven to work, such as needle exchange. Critically, we need a safe and protective vaccine so that every man, woman and child can be protected from this devastating infection.

Finally, we need to recognize that while we have a partially controlled disease in the United States and reduction of transmission, we are looking at an international epidemic that involves 16,000 new infections, including 1,500in children, each year. For moral, biologic and even selfish reasons, we

need in this country to perform research that will address these very critical issues. Because these issues will also eventually affect us as well.

I would like to thank you for your support in the past, and urge you to continue to support a strong NIH, to continue to support HIV/AIDS research. Because without it, HIV/AIDS will become the number one health concern of all nations, including ours. I have submitted detailed written testimony and an appendix which talks about the broad benefits of AIDS research.

Chairman Porter, members of the committee, thank you for this time.

[The prepared statement of Arthur J. Ammann, M.D., follows:]

[Pages 930 - 942--The official Committee record contains additional material here.]

Mr. Porter. Dr. Ammann, thank you for your testimony. I think I can assure you that the subcommittee will continue to place HIV/AIDS at a very high priority. We were happy to see that the President's budget gave it that priority in his judgment.

Because you're our first witness and have mentioned the 15 percent increase that others have mentioned, you get subjected to my sermonette that I have subjected all of our witness groups to. And that is that we have to realize that first, the budget is not in balance yet. The President has submitted a budget that is in balance, in fact shows a small surplus.

But as part of that, he includes about $100 billion of new revenues. I think it's fair to say, and Mr. Hoyer may wish to correct me if he sees it differently, that those revenues are in this year at least highly problematical, and that a lot of the funding increases that the President suggests in discretionary programs are dependent upon revenues that may not, in my judgment, probably will not, materialize in the budget process.

So that means that if you're really interested in the 15 percent increase, the budget committee is where the action is going to lie, at least in the first instance. I would urge persons that are concerned, not only with biomedical research, but with all the programs before the subcommittee, that we can't do very well if we don't have the kind of allocation from a budget that reflects it that will give us the resources we need to make these kinds of judgments.

So that's my sermonette for today. We've got to aim ourselves at the budget process in the first instance and work for a good, strong allocation that will allow us to do the things that we'd like to do.

Do you want to take issue with that, Mr. Hoyer?

Mr. Hoyer. Well, Mr. Chairman, I think clearly some of the spending included in the President's budget is contingent upon revenues being generated. That is not a sure thing. The Chairman's right on that. Therefore, it will not be sufficient to simply focus on this committee's appropriation of funds, but also to focus on both the budget committee and other

committees, authorizing committee, which may impact on that revenue stream. The Chairman's correct on that.

I think what the President has done properly is to project revenues that might possibly occur and set forth a plan to invest those resources in the event that the resources occur. Frankly, from my perspective on the tobacco settlement in particular, that is added reasons for the Congress to act on this matter. I'm hopeful that they will.

But I think the Chairman's correct, that the money's not in hand at this point in time. I would comment, however, that I am very pleased that the President, for the first time in 30 years has projected a balance in light of the projections he has made. That has never occurred, whether the revenues were problematic or not.

This is the first budget that has suggested that it was going to be in balance. And I think, the President is rightfully very proud of that. We on our side are proud of that. I think the Republicans can be proud of it as well, to the extent that the ability to do that was in some respects a joint effort. I think the Congress will want to stick with that, and in fact, reach the balance. But that will put added pressure on making sure that the revenues do, are realized.

Thank you, Mr. Chairman.

Mr. Porter. Thank you, Mr. Hoyer. My sermonette number two is let's keep this strong economy going, because it's creating the revenue stream that allows us to do all of these things.

Thank you, Dr. Ammann, for your testimony.

Mr. Hoyer. He didn't add as a result of the 1993 economic program at present, but I'm sure he meant that.

Mr. Porter. No, I didn't, and I didn't on purpose. It resulted from a private sector which reorganized itself in ways to be competitive over a long period of time, and we've achieved that.

Tuesday, February 3, 1998.

WITNESS

ROBERT M. TOBIAS, THE NATIONAL TREASURY EMPLOYEES UNION

Mr. Porter. Robert M. Tobias, National President, the National Treasury Employees Union, testifying in behalf of the Union. I recognize Mr. Hoyer.

Mr. Hoyer. Mr. Chairman, I'm pleased to have the opportunity to say just a word about Bob Tobias. Bob Tobias is, as you know, a President of the National Treasury Employees Union, and in my opinion, one of the most articulate, able, forceful and visionary leaders that we have representing working people in this country.

He happens to represent Federal employees who are a part of that large working group that keeps this country going. I'm pleased to welcome him to our committee. He's a lawyer, an outstanding background as a Federal employee and now as a leader, frankly, in the reform effort at the Internal Revenue Service, many of whose employees are members of his union.

He was on the commission that recommended reform, and he

has been working, I know, very closely with the new director, Mr. Rosatti, who told me the other day that I was absolutely correct in my judgment that we ought to spend a lot of time with Bob Tobias in working towards reforming the IRS, making it work better, more user friendly and more effective and efficient a service to the American public. So I'm pleased to welcome Bob to our committee.

Mr. Tobias. Thank you, Congressman Hoyer, and Mr.Chairman. I am very pleased to be here to speak on behalf of the employees of Health and Human Services.

Mr. Chairman, Congress spends a great deal of energy and effort creating policy and then designing programs, but very little time thinking about whether or not the program, the policy that's been created and the programs that have been designed are actually implemented in a way that impacts on the public in the way the policy was created and the program was designed.

It seems to me that as the board of directors of the Executive Branch, which is how I see the relationship as it impacts on the employees of the Executive Branch, I ask that you spend some time thinking about the problems of program implementation. Now, those who are responsible for program implementation, the Federal employees in HHS, have a very low morale.

And for good reason. There are 300,000 fewer employees, but no reduction in mission. There are new roles, new responsibilities, but no increase in training budgets, so that people can acquire new skills in order to deliver a changed work process to the public. The continued threats of reductions in force create fear in the work place.

And morale makes a difference in the quality of the products delivered. There's a great deal of data in the private sector, and we're developing similar data in the Federal sector, that when employees say they are satisfied on the job, when their job satisfaction is high, they also deliver better service to the public.

So there's a direct link between the training funds you provide, the technology you make available, and the stability that you provide in the work place to the service that the public receives.

Now, these are issues, I believe, too long ignored. Many in Congress have merely assumed that eliminating 300,000 positions will have no impact on the service delivered, that this effort has merely eliminated the so-called deadwood.

I can assure you that the reduction in agency budgets, in particular, in the training provided, has made service delivery much more difficult. Federal employees want to do a good job. I ask that you not only consider policy and programs, but also program implementation. That in your role, you ensure that employees receive the training they need and the technology they need in order to deliver the programs that you work so hard and debate so long to create.

Thank you, Mr. Chairman.

[The prepared statement of Robert Tobias follows:]

[Pages 946 - 953--The official Committee record contains additional material here.]

Mr. Porter. Mr. Tobias, I think you make very good points. Obviously, part of the reduction in work force should relate to the turning over of the detail, at least, of policy to the states and local governments. We have done a great deal more of that, and we should need fewer people at the Federal level to carry out policies that rely much more upon other levels of government.

But I think you're absolutely right about providing for the morale of Federal employees and funds for training them. I might add to that also, to pay them fairly. I think we attempt to do the best job we can within the limits of our resources to do that. But obviously, we're going to take a look at that and try to do better.

Mr. Tobias. Thank you.

Mr. Porter. Mr. Hoyer.

Mr. Hoyer. I just want to make a brief comment on that. I think you're correct, obviously, where we have shifted responsibilities. In fact, of course, the way we reduced the Federal employee complement of personnel was not to look at mission and work load, it was to simply look at numbers and dollars.

As you recall, what we did was, we ultimately came to the 273,000, which we have now exceeded by almost 60,000, where we have the lowest work force we've had since the Kennedy Administration. What we did was, we determined a good objective, that was fighting crime in America, which has been very successful. We then set up a trust fund, as you recall, to fund that heightened crime fight.

And that trust fund was established from the reduction in Federal employees, so that the necessity for the money and the objective of simply reducing the work force drove us more than making a comparison between work loads and complement necessary to accomplish those work loads. I think that's an excellent point that Mr. Tobias is making.

Obviously you are correct, when we shift, when we either downsize workload then we can reduce personnel. Or when we shift work to either the private sector or to the states and municipalities, we can downsize Federal personnel. Unfortunately, we went at it backwards, and we need to make sure that there is a relationship between work load and numbers of personnel available to accomplish the work load objectives that the Congress and the President set.

Mr. Tobias. Mr. Chairman, you mentioned that the private sector had done a great deal of reorganizing over the past 10 years. I think that what Congressman Hoyer is saying is right on the mark, very few companies have downsized by establishing a goal of downsizing without first identifying what their mission is, what the appropriate structure ought to be to support that mission, re-engineering the effort to produce the service as the Federal Government has done.

So what we find is, some agencies have done that work, many have not. So we have no reduction in mission, no re-engineering. We still have the same responsibility to be delivered with untrained employees without the technology they

need. That obviously creates a work place with low morale and low service delivery.

Mr. Porter. I'd love to continue the discussion, but Mr. Tobias, we thank you for your testimony. I think you have pointed out matters that should concern this subcommittee and do.

Mr. Tobias. Thank you very much.

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WITNESS

VICKI MODELL, THE JEFFREY MODELL FOUNDATION

Mr. Porter. Our next witness is Vicki Modell, the Vice President of the Jeffrey Modell Foundation, testifying in behalf of the Foundation.

Ms. Modell, it's nice to see you again. We are great fans of your commitment.

Ms. Modell. Thank you very much, and good morning, Mr. Chairman and members of this committee.

I'm honored to have the opportunity to testify before you again this year to talk about success. Success that this committee helped to create. But I'll also talk about some things that remain to be done.

When I testified the first time in 1996, the Jeffrey Modell Foundation was a small, grass roots foundation, representing more than 500,000 Americans, mostly children, and a like number of undiagnosed with something called primary or genetic immune deficiency.

Previously, these families had no voice, no visibility in the media, little research at the NIH and most tragically, very little reason to hope. These children were chronically and oftentimes fatally ill. Their prospects for effective treatment were dim and a cure was remote.

I understood their pain and suffering. I understood it too well, for we had faced the same pain with our son Jeffrey, who unfortunately and tragically was taken from us at the age of 15.

But soon after our loss, my husband and I came before this committee with an idea and a plan, a simple, yet comprehensive plan to help these children as quickly and as efficiently as we could through a partnership with the National Institutes of Health. We asked for a hand, not a handout. And offered to fund our share every step along the way with the NIH. We sought your encouragement and support in programs of public awareness, physician education and research. You said yes, and together, hand in hand, we went forward.

Today, I'm here to report back to you that the plan has worked. I can point out with pride that this kind of partnership has now become a shining model for a new form of public-private partnership throughout the campus of the NIH. In the area of public awareness, we created an illustrated ten warning signs poster in English and Spanish that has been distributed to pediatricians and primary care physicians nationwide.

Former Surgeon General, Dr. C. Everett Koop, and NIAID Director, Dr. Anthony Fauci, joined with us in producing an informative video which will target medical schools, school nurses, physician conference and community outreach.

We worked with three NIH institutes and the American Red Cross to produce our seventh symposium for primary care physicians. This one dealt with approaches for diagnosis and treatment using an interactive satellite hookup that was beamed to physicians in 32 cities and 21 States, including the annual meeting of the American Academy of Pediatrics in New Orleans.

At the Genome Institute, where we have funded post-doctoral fellows, the genes that cause more than one-third of these diseases have been identified. That's exciting. We're co-funding with NIAID and NICHD outstanding research projects that would otherwise have gone unfunded, and they are at the University of Washington in Seattle, Children's Hospital in Los Angeles, the University of Florida in Gainesville, and Duke.

To build on the biomedical research, we have redoubled our efforts in clinical research. We now support major research centers at the Mount Sinai Medical Center in New York City, at Boston Children's Hospital and at the Harvard Medical School. It's important to remember that the most effective gene therapy treatments so far have been conducted on our immuno-deficient patients.

We see the results of the clinical research every day. We learn of more and more patients who are diagnosed early and correctly, treated appropriately and are able to lead more normal and productive lives. And isn't that what it's all about?

We've done our part by co-funding with the NIH every step of the way. For all the money we can raise and all the heart that we can pour into this effort, it is becoming increasingly difficult for grass roots organizations like ours to keep up the pace.

I pledge to you that we will continue to do our share. For as you know, we are working in our son's memory, and we will not, nor cannot reset, until this disease is defeated. We need this committee to make clear its strong and unequivocal support and encouragement of what we are doing.

This model of collaboration seems so right. Most importantly, it has worked. I think of it like a kind of circle. It's a circle that connects public awareness to physician education to biomedical research to clinical research, and finally, to clinical application.

In the music from the Lion King, Elton John describes a path unwinding which he calls the circle of life. It's the wheel of fortune, it's a leap of faith, and it's a band of hope. Working together, please let's complete the circle of life and give hope and faith to the half a million children with primary immunodeficiency.

Thank you.

[The prepared statement of Vicki Modell follows:]

[Pages 957 - 963--The official Committee record contains additional material here.]

Mr. Porter. Ms. Modell, I think that you are very much on the cutting edge of what I see to be the future of funding of medical research in our country. Because I think 25 to 30 years from now, I would imagine that half the money going into research will come from private foundations like the one you've established in memory of your son, and will be a very, very important lever to direct research in our country.

So you're there at the opening bell and making a great difference. We very much admire your commitment and your willingness to make a difference in respect to research in this very important area. So thank you for being with us this morning.

Ms. Model. We thank you.

Mrs. Lowey. Mr. Chairman?

Mr. Porter. Mrs. Lowey.

Mrs. Lowey. Mr. Chairman, I want to join you in welcoming and thanking you. I truly thank you and admire you, Vicki, and I see your husband Fred here today, for the extraordinary work you're doing. We all hope that our lifetime can yield some important work, some important difference, can affect the lives of others.

Well, you and Fred have made a powerful difference. I just wanted to express our appreciation. I know that this committee will continue to work in partnership with you so that thousands and thousands of children will have a better life. We thank you very much and thank you, Fred. And we thank all the members of your foundation.

Ms. Modell. Thank you very much. Your words this morning really have made it all worthwhile, and I won't stop now. And I thank you.

Tuesday, February 3, 1998.

WITNESS

STEVEN MIRIN, M.D., AMERICAN PSYCHIATRIC ASSOCIATION

Mr. Porter. Our next witness this morning is Steven Mirin, M.D., Medical Director, American Psychiatric Association, testifying in behalf of the Association.

Dr. Mirin.

Dr. Mirin. Thank you, Chairman Porter and members of the subcommittee. I am pleased to be here today representing the American Psychiatric Association, which is one of the Nation's oldest medical specialty societies, representing 42,000 psychiatrists and just as importantly, millions of our patients.

I'm providing this testimony in collaboration with the statement of the ad hoc group for medical research funding which calls for a 15 percent increase in NIH funding for fiscal year 1999, an important benchmark in the effort to double the NIH budget over the next five years. Chairman Porter, I am mindful of your advice at the beginning of this session.

Today, I will present the APA's specific recommendations regarding the fiscal year 1999 appropriations for the National Institute of Mental Health, National Institute on Drug Abuse,

National Institute on Alcohol Abuse and Alcoholism and the Center for Mental Health Services within the Substance Abuse and Mental Health Services Administration.

The prevalence and impact of mental illness and addictivedisorders is often underestimated. But the magnitude of the problem is significant. Indeed, worldwide, these diseases are among the leading causes of disability. In our own country, when one considers the toll from medical morbidity and mortality, lost productivity, and the costs of treatment and law enforcement, the aggregate burden of severe mental illness now exceeds $300 billion a year.

Thanks to the research advances of the last two decades, we now know that severe mental illness and addictive disorders are not a consequence of inadequate patenting, lack of will, poor self-control or moral failure. They are diseases of the brain whose development is influenced by a host of genetic, biological and psychological factors that are just beginning to be understood.

More importantly, we know that these disorders are eminently treatable, and that the results of treatment are comparable and in some cases better than the treatment for illnesses like heart diseases and cancer. Thus, while the personal and societal costs of mental illness and addictive disorders are high, an investment in research and treatment will help save lives, strengthen families and save taxpayer dollars.

At the NIMH, basic and clinical research has helped lay the groundwork for the development of a new generation of medications for schizophrenia, depression and other mental disorders. These new medications are more effective, have far fewer side effects, and are benefitting more patients than ever before.

For example, NIMH funded research on the anti-psychotic drug Clozapine has helped thousands of individuals afflicted by schizophrenia to leave hospitals and in many cases to hold a job and live independently for the first time in their lives. Economic estimates suggest that the introduction of Clozapine alone saves our Nation approximately $1.4 billion a year in health care and other costs.

But a lot of work lies before us. APA particularly supports NIMH's commitment to expand research on mental illness in children. An estimated 20 percent of American youth, 11 million people in all, have serious emotional or behavioral disorders. Two-thirds of those are not getting any treatment at all.

The effects of these illnesses on the lives of our children and on their families are enormous. Children with untreated cognitive or emotional disorders cannot learn or benefit from the kind of peer and family relationships essential to becoming a healthy and productive adult. These children are also at increased risk of alcohol and drug abuse, criminal behavior and suicide. We urge continued support for the child health initiatives currently underway at NIMH.

Turning to drug addiction, this is clearly one of the most serious problems our Nation faces. The economic and social costs are staggering.

In addition, illicit drug use is a major factor in the spread of infectious diseases like AIDS, hepatitis, and now treatment-resistant tuberculosis. Because it is such an

important problem, the National Institute on Drug Abuse has developed a broad research portfolio that addresses the most fundamental questions about these disorders, ranging from how drugs work in the brain to how we can reach into families and communities to learn why some people are at increased risk for drug abuse, while others in the same family and in the same neighborhood are immune.

Over the past decade, NIDA-funded research has provided us with a far better understanding of the process of addiction and enabled us to develop increasingly effective treatments for these disorders.

The final NIH priority I will discuss today involves our research efforts on a substance that is legal but kills approximately 110,000 of our citizens each year. Although the use of alcohol is culturally acceptable in our society, we all know the human suffering that alcoholism visits on affected individuals and on their families. Chronic heavy drinking often results in profound medical consequences and alcohol use in pregnant women induces congenital defects, learning disabilities and other disorders.

NIAAA-funded research spans a broad range of important questions in the role of genetic factors in this disorder to promising new treatments like Naltrexone, a medication that helps alcoholics by reducing both their craving for alcohol and the euphoria associated with alcohol intoxication.

For fiscal year 1999, the APA recommends that the research budgets of NIMH, NIDA and NIAAA be increased to levels commensurate with the quality of science being supported by these institutes, including $970 million for NIMH, $720 million for NIDA, and $283 million for NIAAA. These recommendations are inclusive of funds to be appropriated for AIDS-related research and are based on the expert analysis of the scientific opportunities that can be pursued at each institute to ensure future progress in our understanding and treatment of these disorders.

Finally, as we all know, research advances mean little unless those who are ill receive appropriate treatment. In this context, the Congress has called upon the Center for Mental Health Services to exert vigorous Federal leadership in mental health service delivery and policy development. In some States, SAMHSA-funded treatment services constitute almost 40 percent of community based mental health care.

For fiscal year 1999, the APA recommends a funding level of $635 million for CMHS. Included in this number is $30 million to support a new investment which we believe would support the committee's goal of making community mental health services more accountable and more cost effective. States need to develop the capacity to collect, analyze and report performance data for the services provided to your constituency.

We urge the subcommittee to appropriate this money to help States develop and implement a data gathering system to accomplish this goal, and to incorporate the use of practice guidelines and measures of treatment outcome as an integral part of service delivery. We stand ready to work with CMHS and the States to improve the effectiveness of these programs.

In conclusion, the APA applauds your leadership in providing support for research and treatment of patients with

mental illness and addictive disorders. These are dollars that are well spent. It will help translate the promise of scientific discovery into improved lives for millions of Americans.

I thank the committee for the opportunity to testify today.

[The prepared statement of Steven Mirin, M.D., follows:]

[Pages 968 - 994--The official Committee record contains additional material here.]

Mr. Porter. Dr. Mirin, thank you very much for your testimony.

Let me remind witnesses that the attention span of members of the subcommittee is exactly five minutes. You lose us after five, including questions, I might add. We have a long, long day ahead of us, and we would ask witnesses to stay within their time limits.

Tuesday, February 3, 1998.

WITNESS

QUINCY ABBOTT, THE ARC OF THE UNITED STATES

Mr. Porter. Our next witness is Quincy Abbott, President of The Arc of the United States, representing The Arc, a National Organization on Mental Retardation.

Mr. Abbott. Chairman Porter, members of the committee, The Arc is the National Organization on Mental Retardation, with over 1,000 chapters throughout the country and 140,000 members. I am from Connecticut, and I'm pleased to be its president this year.

Mental retardation is a condition that affects about 7 million of our citizens. A hundred thousand people are born each year with mental retardation. It cuts across racial, educational, social, religious and economic backgrounds. The Federal Government does have a role, and a proud role, in serving our people with mental retardation. From early intervention through special education through vocational rehabilitation, health services, long term services and supports and housing supports, and prevention of future people with mental retardation.

We have a tragic condition in the United States today. There are over 250,000 people throughout the country waiting for services in the community. A copy of our report that details this by State is with my submitted comments.

There are over 50,000 waiting for placements in the community from institutions, nearly 90,000 living at home waiting for residential services. And our data probably under-reports. Many of these families are in desperate, desperate condition. I think back to when my daughter was young. She is now 34, and I'm real proud of what she has accomplished, living in the community.

I'm ashamed of what I had to do to her when she was four and a half and living at home, and there was no family support.

She was a hellion on wheels. Somebody had to be with her every minute of the day. The only relief was when you put her, at age four, I guess you could call it a cage and not a playpen.

Her psychologist and my wife's psychiatrist agreed that we either had to have supports in the home or put her in an institution. At that time, I did not have the money to pay for supports in the home. There was no family support program. At four and a half, she became the youngest person to enter an institution in the State of Connecticut.

During the next few years, she was over-medicated and under-served. I remember in particular her loss of the few words that she knew, like Daddy. Well, family support can provide assistance to families like mine today. The respite services they need, so the mother can go out and do shopping, or the parents can go out to a movie, it provides only what's necessary. It can save a tremendous amount over the option of institutional costs. Institutions average $75,000 a year in our country, and $5,000 or $10,000 can go an awful long way toward helping a family with family support.

The respite, doing household chores, parent training, especially with newborn infants, property repair. There are families that have used their support payments to repair the house once a year from the damage that's been done by their child, but they still want to keep the child at home. And vouchers for special purposes, special equipment, that sort of thing.

Family support has been authorized for a number of years, but it has never been funded. This year, we're happy that the President's budget contains $5 million to start a Federal funding of family support. We are asking this committee to appropriate $10 million to the States to allow all States to participate in this sort of program.

A very small investment in a family, while the child is young, can reap tremendous benefits down the line. It can enable the child to lead a productive life, as he or she grows up, to become a tax paying citizen and to be off the relief rolls to a large extent.

But the cost savings aren't what's important, it's keeping the family together when the family wants to stay together. That's the important thing.

I thank your committee for its past support, and I hope for your future support.

[The prepared statement of Quincy Abbott follows:]

[Pages 997 - 1003--The official Committee record contains additional material here.]

Mr. Porter. Mr. Abbott, thank you for your testimony.

Can you tell us when the program was originally authorized?

Mr. Abbott. It was authorized, I think, four years ago, in 1994.

Mr. Porter. But there's been no funding?

Mr. Abbott. Yes.

Mr. Porter. Okay. We'll do the best that we can.

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WITNESS

LYNDA JOHNSON ROBB
WILLIAM E. TRUEHEART, READING IS FUNDAMENTAL, INC.

Mr. Porter. Our next witness is Lynda Johnson Robb, Chairman of the Board, Reading is Fundamental, Inc., accompanied by Dr. William E. Trueheart, President of the Corporation, testifying in its behalf.

Lynda, it's nice to see you again. I want to say that obviously, we count you as one of our celebrities who come to visit our subcommittee. But you're more than that. You're committed to this program, you work on it. You personally put your time and effort into it, not just to come to testify, but to be there and be a part of it. We very much admire that commitment, and thank you for being with us.

Dr. Trueheart, welcome.

Mr. Porter. Mr. Hoyer.

Mr. Hoyer. I'd like to say a word of welcome. Obviously, I've known Lynda for a very long time. She was a mere child when I first met her.

But I made this comment, as you have made this comment in the past. There are some people who are celebrities in many ways. Lynda of course is from a family who has given extraordinarily of themselves, her father, of course a great leader in making sure that we did not forget people who were in need in America. He himself had experienced a life, an early life not of wealth, and knew that there were struggles out there. He reached out to people.

The war on poverty has been scoffed at some, I think,frankly it was more that we gave up in some respects than we were defeated by poverty. It was a statement, however, that the richest Nation on the face of the earth knew it had a moral and intellectual responsibility to make sure that every American was given the opportunity that is America's promise.

Lynda and her husband have pursued that life of service and of commitment. Lynda, I want to congratulate you. There is never a year that goes by that I don't, Doctor, have a long conversation with Lynda, so I know exactly what I'm supposed to do, when I'm supposed to do it and who I'm supposed to talk to. Lynda is a very able advocate, Dr. Trueheart, as I'm sure you know. You will find her a great partner in this effort.

Thank you, Mr. Chairman.

Mr. Porter. Thank you, Mr. Hoyer.

Ms. Robb. Thank you, Mr. Chairman, for your kind words. I have been a volunteer for over 30 years for Reading is Fundamental.

We appreciate the opportunity to testify today. We operate the inexpensive book distribution program under a contract with the Department of Education. I request that our testimony be put in the record.

RIF does not replace trained reading teachers. Instead, we motivate children to read and to make sure that they have books to call their own. We have programs in every State, and our 225,000 grass roots volunteers are one of the largest groups of

non-political volunteers in the United States.

We recently received an A plus rating as one of the ten most effective charities in the country from the American Institute of Philanthropy. For every Federal dollar invested, RIF programs leverage more than $5 in private support.

RIF works in partnership with the Federal Government, and I sincerely believe that we are one of the Government's best investments. Locally, RIF projects receive Federal money only for books, not for other costs. For every member of RIF's lean staff, 57,000 children are served.

Local groups made up of teachers, parents and other volunteers make all the key decisions. Working together, we reached 3.3 million children in 1997 with our book distribution program. These 4,000 local RIF programs are sponsored by every group imaginable, from churches to Kiwanas to the Maryland Federation of Republican Women.

Now, let me introduce our new President, Dr. Bill Trueheart.

Mr. Trueheart. Thank you, Mr. Chairman, and thank you, Ms. Robb.

I'm honored to be here today as the new President of Reading is Fundamental. The need for intervention to improve children's literacy is urgent and growing throughout our Nation. The demand for our services requires us to serve increasing numbers of children.

That is why we're here today. Reading is Fundamental respectfully requests a fiscal year 1999 Federal appropriation of $18.3 million for the inexpensive book distribution program.

In 1996, the U.S. Department of Education estimated that approximately 6.4 million children in grades kindergarten to third were in danger of becoming illiterate. The evidence on the likelihood of increasing rates of illiteracy for our neediest children is very, very compelling.

I believe that we cannot let another generation of children grow up without the essential tools to become literate citizens.

In 1993, 1994 and 1995, Congress required Reading is Fundamental to send out a call for applications to test the demand for RIF's services. The response was overwhelming. More than 2,000 local volunteer groups from every State applied, eager to serve approximately 1.3 million children, 85 percent of whom were low-income, without access to libraries, received free or reduced lunch, and were at risk of educational failure.

These children, because they had to be placed on the Reading is Fundamental waiting list, remain there to this day, because we were unable to secure sufficient funds to serve these additional children, despite persistent efforts to raise private funds. The inexpensive book distribution program has been level funded since 1994 at $10.3 million.

Unable to fulfill the needs of this enormous waiting list, RIF stopped requesting applications for participation in the inexpensive book distribution program. Although requests for help continue from every corner of this country.

Had we continued to request applications, we estimate that our waiting list for these literacy services would total at least 4,000 additional volunteer grass roots groups prepared to serve more than 2.6 million additional children.

As the new President of Reading is Fundamental, I was saddened to learn that Congress had requested solicitation of applications for the inexpensive book distribution program but was unable to fully respond to the demand thus created. At present Federal funding levels, RIF cannot meet the demand of local educators, parents and community leaders who recognize the demonstrated value of RIF's reading programs, and who want those vital services for their children.

Although RIF received an increase in fiscal year 1998, for which we are very grateful, that $12 million appropriation will serve only an additional 300,000 children. A million more will remain on the waiting list unless Congress takes action now.

For a Federal investment of $3.07 per child, RIF's partnership with the Federal Government can provide new books, reading programs and assistance to parents and volunteers who are committed to a literate future for our neediest children. In making this request for increased funding, we are not asking the Federal Government to bear the responsibility alone. RIF allocates funds only to local groups who meet stringent criteria demonstrating that they are unable to operate without Federal assistance to provide books to the children in these communities.

Mr. Chairman, I understand that I've run over, so I will move to my conclusion. I believe it would be unfortunate to deny yet another generation of the Nation's neediest children access to proven effective and fundamental reading readiness and motivational programs, when our Nation has the human and financial to eradicate illiteracy now.

At a minimum, we ask you to provide additional funding to eradicate the longstanding waiting list generated at Congress' request so that literacy services can be provided as soon as possible to those 1 million educationally at-risk children.

Thank you for your past support, and I respectfully urge your continued and increased support for Reading is Fundamental and the inexpensive book distribution program.

[The prepared statement of Lynda Johnson follows:]

[Pages 1007 - 1012--The official Committee record contains additional material here.]

Mr. Porter. Dr. Trueheart, give me your funding level again that you're suggesting.

Mr. Trueheart. It's $18.3 million, sir.

Mr. Porter. We appreciate very much your testimony this morning. I got an education back in 1995 when this subcommittee was required to make so many budgetary cuts in order to meet our deficit reduction guidelines. I heard from a lot of people.

You're right, there's 225,000 out there, I think, because we might have heard from all of them. [Laughter.]

I'm not so sure they're not political. But in any case, I learned a lot about the program that I did not know before. I really did learn a lot about the program and have learned to value it, perhaps much more highly than I did previously. We appreciate your coming here today to further educate us. We're going to do the best we can to provide you the resources that

you need to get the job done.

Thank you.

Ms. Robb. Thank you.

Mr. Trueheart. Thank you very much.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Tuesday, February 3, 1998.

WITNESS

SUSAN JOHNSON
JOSEPH McNULTY, HELEN KELLER NATIONAL CENTER FOR DEAF-BLIND YOUTHS AND ADULTS

Mr. Porter. Sue Johnson, parent of a deaf-blind young man, accompanied by Mr. Joseph McNulty, Director, Helen Keller National Center for Deaf-Blind Youths and Adults testifying in behalf of the Center.

Ms. Johnson and Mr. McNulty.

Mr. McNulty. Thank you, Mr. Chairman. We appreciate the opportunity to testify.

The Center is seeking an additional $1 million in our fiscal year 1999 appropriation. Speaking on behalf of the Center this morning is Ms. Susan Johnson.

Ms. Johnson. It's an honor and a pleasure to be here to talk to you this morning. I'm the parent of a 21 year old deaf-blind child who has been making his way through the system for the past 21 years. As he has, and as we've tried to raise him, Helen Keller National Center has been our one and only support system through that process.

When Jake was 16 years old, he began to experience extreme difficulty in every point of his life. The public school system could no longer serve him, and he was placed in an institution at the cost of $70,000 a year.

During those 18 months that Jake was in an institution, it was the hardest time in our lives that we had ever faced with Jake. I began to call Helen Keller National Center over and over and over. They began to help me through the process of getting Jake out of an institution and to Helen Keller National Center to be reevaluated and retrained and try to get him back in our family and in our society.

We're happy to say that Jake is now 21. After spending 20 months at Helen Keller National Center, he is living in a home of his own and working at Olive Garden five days a week rolling silverware. We're incredibly proud of him and very, very thankful for the work and the commitment that Helen Keller National Center made to our family and other people like Jake, who are born without vision and hearing.

Throughout the rest of Jake's life, we expect that Helen Keller National Center will be a part of our life. It's the only resource for deaf-blind people in this United States. There are 11,000 deaf-blind children throughout the United States, and Helen Keller National Center is their resource and their families' only place to turn for help and education.

As Joe said, they are asking for another $1 million in funding this year. And that will be to serve people like Jake who have graduated from Helen Keller, who are making it in the society. But as his life goes on, he has hurdles. Our only place to go is to them for help and support.

We hope that you will look very seriously at this request and grant it for us.

[The prepared statement of Susan Johnson follows:]

[Pages 1015 - 1020--The official Committee record contains additional material here.]

Mr. Porter. You're not going to say anything?

Mr. McNulty. Not at all.

Mr. Porter. You don't need to after that presentation.

Mr. McNulty. That's right.

Mr. Porter. We really appreciate it, Ms. Johnson. You couldn't have stated the case better, and obviously we're going to do the very best we can to accede to that request.

Ms. Johnson. Please look closely.

Mr. Porter. Mr. Hoyer.

Mr. Hoyer. I should know the answer to this question. Where's the Helen Keller Center located?

Mr. McNulty. The headquarters is located up in New York, on Long Island. We operate 10 regional offices, and we have affiliations with 44 State and local agencies throughout the country.

Mr. Hoyer. You're from New York, did you access it that way?

Ms. Johnson. Actually, we're from about everywhere, because my husband's in baseball. We're in a bunch of different States. But we're actually, our home is in Florida, and then Jake actually went to Long Island and lived there for 20 months and lived on their campus.

Mr. Hoyer. Your husband's in baseball?

Ms. Johnson. Yes, sir. My husband's David Johnson that used to be with the Orioles.

Mr. Hoyer. Who did he play for? [Laughter.]

We're glad to have you here, and it's nice that you brought him along.

Ms. Johnson. I'm glad he came with me.

Mr. Porter. Thank you very much, Ms. Johnson.

Mr. Hoyer. Obviously, Jake has two great parents. That's an important aspect in his life.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Tuesday, February 3, 1998.

WITNESS

JOHN S. GUSTAFSON, NATIONAL ASSOCIATION OF STATE ALCOHOL AND DRUG ABUSE

DIRECTORS, INC.

Mr. Porter. John S. Gustafson, Executive Director of the National Association of State Alcohol and Drug Abuse Directors, Inc., testifying in behalf of the Association.

Mr. Gustafson. Good morning, Mr. Chairman and members of the subcommittee.

Mr. Porter. Good morning.

Mr. Gustafson. Thank you for the opportunity to testify before you today, and to make our recommendations for the increased investment in alcohol and other drug prevention treatment and research services.

Specifically, we are supporting a 15 percent increase of $254 million to the Substance Abuse block grant that is currently funded at $1.36 billion. The funding level of $1.36 billion includes the two year transfer of $50 million appropriated to provide treatment services to the former recipients of SSI and SSDI. Although the legislative authority for this additional $50 million was only for 1997 and 1998, we are urging that this level of funding be maintained based on the need for treatment.

We also are supportive of funding increases for the knowledge development and application programs within the Centers for Substance Abuse Treatment and Centers for Substance Abuse Prevention as well as the Safe and Drug Free Schools Program and the research budgets for NIDA and NIAAA.

In supporting these increases, Mr. Chairman, we emphasize the need for new and stronger linkages between these Federal programs and the substance abuse block grant that is the primary commitment of Federal resources for prevention and treatment in partnership with the States. Our national association represents the concerns of State alcohol and drug abuse directors who administer and fund prevention and treatment programs to a network of some 7,000 community based not for profit organizations.

I would like to discuss briefly three issues with you today. First of all, welfare reform and the need for treatment. It is estimated that over one million welfare mothers have substance abuse problems that require treatment. As welfare reform is implemented, States are under pressure to find the resources needed to provide treatment services to get these mothers back to work.

There are now long waiting lists for treatment. Without new resources, it will be difficult for moms receiving temporary assistance for needy families, TANF, and others in need to receive appropriate treatment.

Secondly, prevention. Prevention of alcohol and other drug problems in our youth remains a very high priority. As a Nation, we continue to be alarmed by the number of youth who are initiating alcohol and drug abuse. The Office of National Drug Control Policy, ONDCP, has begun its media campaign in earnest. Now it is up to the States to providethe prevention and treatment resources that can logically be expected as a result of that campaign.

Mr. Chairman, our country's substance abuse problem is enormous. Over 13 million Americans use illicit drugs. Nine million youth under the age of 21 consume alcohol. Of these, 4.4 million are binge drinkers, including 1.9 million heavy

drinkers.

On an annual basis, the publicly supported State alcohol and drug abuse system administers about $4 billion of substance abuse services annually. States spend over $583 million per year on prevention services. About 1.9 million treatment admissions comes into that system every year.

Every year, we conduct a waiting list of our members to determine the need for treatment, and included in the written testimony is a state by state breakdown for members of this committee as to how those waiting lists play out.

NASADAD is well aware of how important our treatment system is to getting TANF moms and others back to work. We have been working closely with the Department of Labor and the private industry councils to help ensure the success of the two-year welfare to work program. One thing that is clear to all of us, State administrators, providers of services, employers and welfare experts, and that is that the long waiting lists for treatment are a barrier for getting these moms back to work.

It is also clear that unless TANF recipients get the treatment they need, job retention will be a major problem for families, States and employers.

Now, if we're successful in convincing members of the Congress to make these additional appropriations, let me just highlight very briefly some of the services that States would be prepared to engage in. First and foremost, reduce the number of people on current waiting lists. Develop new services for women TANF recipients, such as weekends or evening treatment programs, and lunch prevention education programs. Establish employee assistance programs for those that hire welfare recipients. Create new mentoring programs that engage business leaders in reaching out to youth to build esteem and life skills, as well as avoid substance abuse.

Quite often at these hearings, we are asked to speak to the treatment effectiveness issue. I would commend to the committee's recommendation two very recent studies, one conducted by the National Institute on Drug Abuse entitled the Drug Abuse Treatment Outcome Study and the second by SAMHSA, Substance Abuse and Mental Health Services Administration, the National Treatment Improvement Evaluation study. Both are long term, longitudinal studies that point to the clear benefit of treatment in terms of reducing illicit drug use, increased productivity and reducing illegal behavior.

I want to conclude, Mr. Chairman, with reference to an issue that's been somewhat contentious, both on the authorization side and certainly on appropriations. That is the formula that forms the basis for delivering the block grant monies to the States. Our membership takes very seriously the admonition from the appropriators last year to try to come to agreement and consensus on how to best distribute these funds.

We have recently convened a meeting of our members and compiled a set of recommendations that is being embedded throughout the entire State membership. One of the major issues we want to avoid is the serious disruption that is created by a dramatic shift in the formula indices from one year to another. As I mentioned, most of these providers are local not for profits. When you have one State move in a positive direction of 20 percent and another State in the opposite direction, it

creates massive disruptions of services, and actually throws people out of treatment.

My written testimony provides detailed recommendations as to how we would like the formula to be considered. We are working hand in glove with the authorizers to make our recommendations known.

Thank you very much for the opportunity to testify, and I look forward to responding to any questions that you may have.

[The prepared statement of John S. Gustafson follows:]

[Pages 1024 - 1039--The official Committee record contains additional material here.]

Mr. Porter. Mr. Gustafson, tell me again what increase you're recommending and on what base.

Mr. Gustafson. On the base of $1.36 billion for the current block, we are recommending an increase of $254 million.

Mr. Porter. And what percentage would that be, do you know?

Mr. Gustafson. Approximately 15 percent, Mr. Chairman.

Mr. Porter. All right. Thank you very much for your testimony, Mr. Gustafson.

Mr. Gustafson. Thank you, sir.

Tuesday, February 3, 1998.

WITNESS

ADA SUE HINSHAW, AMERICAN ASSOCIATION OF COLLEGES OF NURSING

Mr. Porter. Our next witness is Ada Sue Hinshaw, Ph.D., R.N., Dean of the School of Nursing at the University of Michigan in Ann Arbor, Michigan, testifying in behalf of the American Association of Colleges of Nursing.

Ms. Hinshaw, it's nice to see you again.

Ms. Hinshaw. Thank you. It is nice to again be in front of the committee and have an opportunity to let you know about the issues and concerns for the American Association of the College of Nursing.

In addition to the introduction as Dean of the School of Nursing at the University of Michigan in Ann Arbor, I do want to clarify that I was the Director of the National Institute for Nursing Research for seven years. That's important in light of my testimony, so I want to be sure you know where my biases stand early, and very fast.

For fiscal year 1999, AACN is recommending a 100 percent increase for NINR over the 1998 budget to $127 million. For AACPR, we are asking for an increase of 10 percent to slightly over $161 million.

For the Nurse Education Act, we are requesting an increase of 8 percent over 1998 to a level of $70.9 million. For the scholarships for disadvantaged students, we seek an increase of 8 percent over the 1998 level to $20.235 million.

Now what I'd like to do is primarily speak to our very strong recommendation for the NINR. There are three reasons that we are really pursuing a doubling of the resources to this

particular institute at NIH.

As unusual as this is, at this point, NINR is literally fighting success in terms of its research programs and its research training programs. It's a good phenomenon in the sense of the kinds of research that is being produced, the number of researchers who are now engaged in very exciting projects around promoting health, around increasing the care of the chronically ill individuals, of providing increased care for the acute nature of the hospitals that we are currently working in. And also looking at the health care systems themselves as they impact the client and the patient incomes in terms of quality and cost.

All of these kinds of research programs are parallel and very complementary with the biomedical research mission.

Secondly, nursing science has now advanced rapidly to the point in which we are conducting a number of clinical intervention studies. Intervention studies are more intensive in terms of resources. They take a longer number of years to conduct. Therefore, the amount of resources which need to be invested in any one research study over a period of time is much greater than it was earlier in the past 12 years, a decade ago, rather, when the institute began.

The research training needs for nursing are also stillquite high. And there is a drain of nursing faculty, as there are many of our people in the country. And there's going to need to be a change, a new cadre of individuals who are brought along and allowed and helped to mature over this time.

I would like to also suggest that we look at the fact that the NINR has the smallest funding level of any institute in most of the centers at the NIH. Literally, the funding base is less than one-third of the next closest institute. Even doubling, or requesting a doubling of the money to $127 million, the next institute is over $200 million in terms of support.

But that is not really the reason for why we need to really look at increasing the resources for this particular institute. The reasons are the differences that the research is beginning to make. For example, the nursing research focuses heavily on cultural relevant kinds of health care, providing recently a new study at UCSF Arthritis Center in California in which it is clear that now Spanish speaking language programs for our people with arthritis are now available to Spanish populations in that area. Community outreach, classroom education, etc.

Another example is that today's shorter hospital stays save money, but quite frankly, they mean that patients go home sicker at discharge and they need more support at home. So the studies that NINR have funded, an entire series of them that look at comprehensive discharge planning, and then follow-up in the community by advanced practice nurses, have allowed in a series of about four to five populations now for a savings of health care in general between 27 and 37 percent per case.

So these are very important and very exciting studies. They are tracking both quality of care and cost of care.

A third study that is very important, is going to be making a difference, is that different types and intensities of pain trouble patients and quite frankly, challenge caregivers a great deal, such as nurses. An NINR-funded research study has

discovered that for women in particular, a type of pain medication, kappaopioids, more effectively reduces high levels of intense pain than morphine drugs and has fewer negative side effects.

This study as well will now be replicated and followed up on as an exciting area of research having to do with symptom management.

Essentially, I would simply like to speak for a few minutes, for a few seconds, excuse me, I heard the buzz, to the Nurse Education Act as a key source of Federal financial support for nursing education programs and nursing students. We are seeking an 8 percent increase for the NEA for this coming year.

I thank you and would entertain questions.

[The prepared statement of Ada Sue Hinshaw follows:]

[Pages 1043 - 1050--The official Committee record contains additional material here.]

Mr. Porter. Dr. Hinshaw, thank you very much for testifying. I might say to you and to all the witnesses that as I sit here and listen to the very compelling testimony, I think that it is probable, with the kinds of increases in each of the areas that are being requested, are probably a year off in reality. And that we have to continue to see the kind of economic growth that we've seen recently continue in order to achieve them.

I want to assure all of you that we will do the best we can within the resources we have to meet the needs that are very obvious, and all of our witnesses have mentioned in a number of different areas. I think probably it's going to be a little longer time than all of us would want, and dependent upon a strong economy.

I think eventually we will get there, and probably sooner rather than later. Thank you for your testimony, we appreciate it very, very much.

Ms. Hinshaw. Certainly. Thank you for your consideration.

Tuesday, February 3, 1998.

WITNESS

EILEEN BREWER, M.D., AMERICAN SOCIETY OF PEDIATRIC NEPHROLOGY

Mr. Porter. Eileen Brewer, M.D., President, American Society of Pediatric Nephrology, testifying in behalf of the Society.

Dr. Brewer. Chairman Porter and members of the subcommittee, I'm the current President of the American Society of Pediatric Nephrology. In my other life, I'm a faculty member of Baylor College of Medicine and Chief of the Renal Service at Texas Children's Hospital in Houston, Texas. I see patients every day, and all of them are infants, children and teenagers with kidney disease.

By way of background, the American Society of Pediatric

Nephrology, or the ASPN, is a non-profit organization that was founded in 1969 to serve as an advocate for the estimate 150,000 children with kidney disease in this country. About 10,000 of these young citizens are already on dialysis, have a kidney transplant or have chronic renal failure that will lead to those modalities.

ASPN represents over 90 percent of the physicians devoted to caring for these children with kidney diseases. One of our principal missions is to promote research that we hope will one day lead to the eradication of these diseases that ravage the lives of this most vulnerable segment of our population.

The ASPN participates with the American Society of Nephrology, the National Kidney Foundation, the American Society of Transplant Physicians and the Renal Physicians Association and the Council of the American Kidney Societies. We as a group support research funding to help all of the Americans that are suffering from kidney disease.

Mr. Chairman, I do want to take this opportunity to thank you and the members of the subcommittee for the leadership you've demonstrated in the past. Because of the support lent by you and members of this committee and your predecessors, this Nation has certainly built a remarkable health record. That progress has had a dramatic impact on the care of children with renal disease as well.

For example, the hereditary disease, cystinosis, which is a metabolic disorder that affects the kidneys, the eyes and the pancreas, can now be treated so as to delay or prevent the worst effects on children. Currently there are two studies in progress, major clinical research studies to find ways to prevent and treat the devastating consequences of two kidney diseases that are particularly common in childhood and adolescence. Those are the hemolytic uremic syndrome and IGA nephropathy.

There have also been remarkable strides in prolonging and improving the lives of children with end stage kidney disease. Kidney transplants now have a better success rate, and even those children and teenagers who remain on dialysis have fewer hospitalizations and they lead a better quality of life.

But each advance enables us to concentrate more on the remaining challenges. About one-third of the children who now have end stage kidney disease were born with congenital renal anomalies. These anomalies prevented the normal formation of or destroyed their kidneys.

We currently do not know enough about basic renal development to aid us in preventing or slowing the progression of renal failure for these children, even if we diagnose their condition before birth. In addition, for each one million children in the United States, 50,000 will develop urinary tract infections which can damage developing renal tissue and lead to permanent scars in the kidney.

About 40,000 more children will require evaluation for hematuria and proteinuria, which are signs of progressive kidney disease. Another 50,000 children will be diagnosed with hypertension that can cause renal failure in adulthood. And an additional 5,000 children will develop diabetes, and 2,000 of these will require dialysis or kidney transplant in late childhood or adulthood.

We must do more to identify and treat chronic kidney disease in its earlier stages in childhood and adolescence to prevent end stage renal disease in later life. In this regard, we support the National Kidney Foundation's initiative to evaluate proteinuria as an early sign ofprogressive kidney disease.

While we've seen progress on several fronts, much remains to be done. When chronic kidney failure occurs in infancy and childhood, normal growth and development are impaired due to a variety of factors which include altered nutrition, impaired bone formation, and resistance to normal growth factors like growth hormone.

While many advances have already been made, including the discovery that treatment with supplemental growth hormone increases growth, most children with chronic renal failure do not obtain the normal adult height. In addition, the effects of kidney failure on the developing brain are very poorly understood. Learning disabilities and mental retardation may be consequences of kidney failure in infancy and early childhood.

More research is needed to better treat and prevent the adverse effects of chronic kidney failure on growth and development in pediatric patients.

Kidney transplantation still remains the therapeutic choice for children with end stage renal disease. Unfortunately, studies show that the improvements we have seen in transplant survival among adults have not been realized in our pediatric patients. We scientists attribute this to many factors, but the most important appears to be the child's own immune system, which seems to be more inclined to reject the transplanted kidney.

If we don't do something to find better survival of transplanted kidneys, about half of all children receiving transplants over the next five years will be back on dialysis by the end of the decade.

We want to commend this subcommittee for asking the NIDDK to develop an interagency plan for adult and pediatric kidney disease, because we feel it is especially important to distinguish between adult and pediatric research. We support the ad hoc group for medical research funding, which calls for a 15 percent increase in funding for the NIH in fiscal year 1999. We also would recommend that this subcommittee allocate $3 million to the NIH for research on the unique needs, including the immunosuppressive needs, of children and adolescents suffering from diseases that lead to chronic kidney failure.

Thank you, Mr. Chairman.

[The prepared statement of Eileen Brewer, M.D., follows:]

[Pages 1054 - 1064--The official Committee record contains additional material here.]

Mr. Porter. Dr. Brewer, thank you very much for your testimony. We apologize to you and all of our witnesses for the tyranny of the bell. Unfortunately, there's so many people that want to testify that we have to limit testimony to five

minutes. For that we very much apologize. Thank you for coming to testify this morning.

The Chair would ask Mr. Bonilla to chair.

Tuesday, February 3, 1998.

WITNESS

RACHEL GONZALES, NATIONAL ASSOCIATION OF COMMUNITY HEALTH CENTERS

Mr. Bonilla [assuming chair]. Thank you, Mr. Chairman.

The Chair would like to call Rachel Gonzales, Chairperson of the National Association of Community Health Centers.

Before Ms. Gonzales begins, I'd like to point out to my colleagues on the subcommittee and to those who are here with us today that Rachel is an example of what it means to truly be a community public servant. When you began your career as a secretary in the clinic 13 years ago, we recall it was housed in a trailer, you had only two exam rooms.

Then you worked your way to the top and the clinic also grew under your guidance. Before too long, you were moved to the current location, which was once a hospital storage facility, and have since created three additional sites where patients can come to receive care that are aside from the current location.

Today through your perseverance and under your guidance, commitment and dedication, as a CEO of the clinic, I was proud to be at the ground breaking ceremony just recently that will eventually house on that site a facility that's five times the size of its current location to accommodate the increase in demand for your quality service that you now have in Uvalde County.

You are a great inspiration for a lot of folks out there, young people who look to someone like yourself and say, gosh, here's somebody who not only can rise to the top in a very brief period of time, and that's one thing, but leave behind all of the great care that your clinic has provided over the years is even more important. Because all of the families that are affected and the people who come in have no place else to go. You made a difference in their lives and I thought I should point that out before you begin your testimony this morning.

Thank you for being here.

Ms. Gonzales. Thank you, Congressman, very much.

Good morning. I appear on behalf of the National Association of Community Health Centers in support of increased funding for 1999 for the Consolidated Health Center program. Health centers provide quality, cost-effective health care to patients in urban and rural medically under-served areas. It is for this mission that we ask the subcommittee's continued strong support.

A written statement has been submitted, so I will only summarize and underscore a few of the pressing issues that face all health centers. First, I want to thank the subcommittee for strengthening the health center program over the last two years. Under the leadership of Chairman Porter, appropriations for the program have increased by $68 million in a period when the subcommittee had to make difficult choices.

We are particularly grateful to Congressmen Henry Bonilla and Jay Dickey for their efforts on our behalf. These new funds are making services available to many more uninsured patients through the establishment of new health center sites in previously unserved areas.

However, there is more work to be done. Most existing health centers have not seen an increase in their grant dollars for the past eight years. Yet, nearly all are inundated with escalating numbers of uninsured people, over one million in the past three years.

Health center revenues from other sources, especially Medicaid, are declining as managed care increases. These centers need additional support to meet the growing needs in our communities.

I'd like to tell you about our health center and the unmet needs of our community. Our agency is a rural community and migrant health center located 80 miles southwest of San Antonio, Texas. Services are provided from two health center sites, one in Uvalde and one in Leakey, serving Real and Edwards County.

The total population of the three counties is approximately 30,000. More than half of whom are members of low income, uninsured families spread across an area that is virtually the same size of Connecticut.

Our agency serves 5,000 people, 58 percent of whom are uninsured, and 65 percent are at or below the poverty level. Most are Hispanic and many are farm workers.

The typical elderly patient of our health center suffers from at least three serious conditions: diabetes, hypertension and congestive heart failure, whose care normally requires anywhere from five to ten different prescriptions. The Uvalde site, with three full time providers, will serve between 75 and 90 patients daily, and fill an average of 90 prescriptions through our in-house pharmacy. The Leaky site, with one full time provider, also has an in-house pharmacy, the only pharmacy anywhere in Real and Edwards Counties.

The needs of our community and its uninsured are growing. at the present time, patients calling for appointments must wait at least two weeks due to our heavy patient load. We are aware of individuals who do not have a family doctor, and when they become ill, wait until their condition has worsened before they seek attention. Then they go to the emergency room.

The same situation applies to many pregnant women. There is not enough obstetrical care in our area.

We currently need at least five more full time primary health care providers. But it is difficult to recruit, and even harder to retain, health care professionals for the trying work of practicing medicine in rural areas. Our resources are not enough to support primary care, healtheducation, and preventive care to all who need it.

If we could hire these additional providers, we could serve 4,700 new patients and provide over 19,000 new office visits annually.

Our story is just one of many across the Nation. As Chair of NACHC, I am speaking on behalf of over 940 health centers in over 3,000 urban and rural communities. Together, these health centers care for over 10 million children and adults, one in

every ten uninsured individual relies on the health center for care.

Our centers are local, non-profit, community owned health care programs that are governed by volunteers who take responsibility to ensure that responsive and affordable health care is provided to all who need it. Patients are charged on a sliding fee scale to insure that income or lack of insurance is not a barrier to care.

A host of studies and reports have shown that the health centers are one of the most efficient health care providers anywhere. Investing in health centers is one of the wisest decisions this subcommittee continues to make.

For example, every $100 million in Federal grant funds leverages another $200 million in other resources and helps provide care to another one million patients. This creates healthy workers and students.

We provide an economic base in our most financially depressed urban and rural communities and create meaningful jobs, including new health care professionals.

An additional Federal investment in health centers would ensure the availability of primary and preventive health care to the growing numbers of uninsured. Priority should be given to strengthening and preserving the existing health center infrastructure.

On behalf of NACHC and the Uvalde County Clinic, I'm asking you to please consider our recommended level of $926 million for the Consolidated Health Center Program for fiscal year 1999. This would ensure us being able to serve an additional 350,000 low income, uninsured individuals.

Invest in health centers. Build upon what has worked. Look at the long history and success of the program, and continue to invest in programs that mobilize communities to solve problems at the local level.

Thank you for allowing me to speak today.

[The prepared statement of Rachel Gonzales follows:]

[Pages 1068 - 1073--The official Committee record contains additional material here.]

Mr. Bonilla. Thank you, Rachel, for your excellent testimony. You know we'll do the best we possibly can on this subcommittee to help you.

Ms. Gonzales. Thank you, Congressman.

Mr. Porter [resuming chair]. Thank you, Mr. Bonilla.

We have departed slightly from our order of witnesses at Mr. Bonilla's request. We now go back.

Tuesday, February 3, 1998

WITNESS

DONALD E. WILLIAMSON, M.D., ASSOCIATION OF STATE AND TERRITORIAL HEALTH OFFICIALS

Mr. Porter. Donald E. Williamson, M.D., State Health

Officer, Alabama Department of Public Health and President of the Association of State and Territorial Health Officials, testifying in behalf of the Association.

Dr. Williamson.

Dr. Williamson. Thank you, Mr. Chairman.

I'm here today representing the Association of State and Territorial Health Officials, and serve as that Association's President. We have the privilege of representing the chief health official in each State and territory of the United States.

If you will allow me to begin with our association's fiscal year 1999 recommendations for Section 317 immunization program funding administered by the Centers for Disease Control, ASTHO recommends $539 million for this critical program. This does represent a significant increase over fiscal year 1998 funding. However, funding over the past several years has been reduced from $528 million in fiscal year 1994 to $427 million in the current fiscal year.

ASTHO is particularly concerned about the President's budget request of $406 million for fiscal year 1999, and feels this is based upon mistaken assumptions about projected carryover.

During fiscal year 1997, States actually spent a total of $539 million. A total of $467 million was appropriated in fiscal year 1997, but States also used carryover dollars from calendar year 1996 to conduct their fiscal year 1997 immunization activities. This indicates they actually needed considerably more funding than was appropriated to achieve the national goal of fully immunizing 90 percent of two year olds.

The latest data on the States' progress provided by the Centers for Disease Control show that in 1996, an average of 78 percent of two year olds were fully immunized compared with an estimate of 50 percent in 1993, before significant increases in the program occurred. States have made excellent progress in achieving our national goal. However, we have not yet arrived.

The cut in fiscal year 1998 funding comes at a time when States are estimated to have reduced their carryover funds for calendar year 1997 by two-thirds. In fact, projected estimates of carryover funds for 1997 are now likely to be considerably below the $60 million assumed last fall.

In addition, it is our understanding that carryover funds are likely to be close to zero for calendar year 1998. The fiscal year 1998 cut in funding has resulted in the following. First, a median cut of 17 to 18 percent in State and territorial immunization infrastructure budgets, state budgets for core activities have been funded at only 74.5 percent of original estimates negotiated by CDC and the States, and third, preliminary reports of ASTHO confirm that States will change the way we're conducting our immunization programs.

Specifically, States are reducing activities, including less provider training, reduction in outreach to communities and parents, reduction in linkage activities to WIC and welfare sites, reduction of administration of shots in local clinics, and elimination of reminder and recall activities. From a public health perspective, perhaps the most ominous reduction is a further reduction in development and implementation of immunization registries.

What the Section 317 immunization program needs for fiscal year 1999 is not further cuts, but rather, a significant increase to avoid the risk of another emergence of vaccine preventable disease, such as measles and whooping cough, which provided the original impetus in fiscal year 1994 for the national vaccine effort.

ASTHO also recommends $705 million for Title V Maternal and Child Health Block Grant which is the amount authorized by Congress to meet the assessed need. Over the past decade, we have seen increased demand for MCH program support due to increasing numbers of uninsured and underinsured women and children. While enactment of the Health Insurance Portability and Accountability Act and the Children's Health Insurance Program are welcome improvements for many, we arefacing a new round of private insurance premium increases which will especially impact the working poor.

MCH programs have not experienced a reduction in demand for services, only an increase. And this can be expected to continue as long as health insurance is unaffordable for many of America's families. MCH programs expect to experience increased demand due to the enactment of the Child Health Insurance Program, because they are an important link in the efforts to locate, assess and refer eligible children for expanded Medicaid and private insurance coverage under the program, in addition to providing direct medical services.

Next, ASTHO urges the committee to provide $182 million in funding in fiscal year 1999 for the preventive block grant, which provides the only flexible funding to States to address critical health problems. This amount is the level that States have estimated is needed in order to maintain continued progress toward meeting the identified Healthy People 2000 goals.

This program, which in fiscal year 1995 was funded at $160 million, has been steadily eroded. Categorical programs are appropriate when addressing national health problems, such as HIV/AIDS and immunizations. But there are no funds for many State and community specific problems except through the preventive block grant.

Finally, ASTHO recommends $90 million for the CDC Office of Smoking and Health for fiscal year 1999. The Office of Smoking and Health has worked to deglamorize tobacco use among teens and to empower youth involvement in tobacco control efforts. The program has particularly worked to provide funding to all 50 States for tobacco control under its IMPACT program.

More must be done, however. Tobacco use is the single largest contributor to chronic disease and premature death in the United States. Smoking rates among high school seniors are at all time highs. And smoking among eighth through tenth graders has increased more than 50 percent since 1991. Without doubt, tobacco use is clearly a problem that begins with children, with almost 90 percent of adult smokers starting smoking at or before the age of 18, and the average smoker beginning at age 13 and becoming a daily smoker by age 14 and a half.

Thank you again for the opportunity to present ASTHO's funding recommendations for fiscal year 1999 on these important public health programs. We appreciate the support this

subcommittee has provided for public health and look forward to working with you during the coming years.

Thank you, Mr. Chairman.

[The prepared statement of Donald E. Williamson, M.D., follows:]

[Pages 1077 - 1085--The official Committee record contains additional material here.]

Mr. Porter. Dr. Williamson, you get the award for getting more words in in five minutes----

Dr. Williamson. Thank you, sir. [Laughter.]

Mr. Porter. Let me ask something, though. It was not very long ago when this Administration made, as a centerpiece of their appeals in the State of the Union address and their budget, the immunization of children. You're telling us now they're underfunding the program. Can you tell me what their rationale is, if you know?

Dr. Williamson. Well, I would not purport to speak for the Administration. But we believe it would relate to their assumptions about carryover. However, and we know this subcommittee has been concerned about carryover, but States have attempted to respond to that concern. Less than half of our States reporting any carryover now.

And the projected carryover, $60 million, which I think that number was arrived at around the first of December, by the end of the month was substantially less when CDC was beginning negotiation with the States. That carryover is in fact, as we understand it, programmed into the fiscal year 1998 operations. And in fact, we expect no carryover at the end of this fiscal year.

I think our real concern, Mr. Chairman, is that while we have made historic progress in immunizing the children of America, that one critical component of that is to ensure that a child, wherever they present for health care, we can find out their immunization status. That really hinges on immunization registries.

And now to pull back those dollars that are critical to finally completing those registries that a lot of us have been working on we fear could in fact certainly prevent further progress and perhaps erode current efforts.

Mr. Porter. Obviously we'll look into this independently, and we'll question the Secretary about it when she appears. We'll try to get to the bottom of it and be responsive to your concerns.

Dr. Williamson. Thank you, sir.

Mr. Porter. Thank you for testifying.

Tuesday, February 3, 1998.

WITNESS

LYNNE V. CHENEY, AMERICAN ENTERPRISE INSTITUTE FOR PUBLIC POLICY RESEARCH

Mr. Porter. Lynne V. Cheney, Senior Fellow, American Enterprise Institute for Public Policy Research, testifying in behalf of AEI. Lynne, we're delighted to see you. We're great admirers of you and your husband. I can't think of two people who have given more in terms of public service to this country than the Cheneys. I have to admit that I thought your husband would have made a wonderful President and you would have made a wonderful First Lady.

Ms. Cheney. Well, how can I top that.

Mr. Porter. Maybe you'll all reconsider.

Ms. Cheney. Thank you very much, Mr. Chairman, and Congressman Hoyer, who's fine State I once lived in, and Mr. Bonilla, whose fine State I am now a citizen of.

I appreciate your having me here today. You've been listening to many concerned citizens who brought forward many worthy causes to be funded by the Federal Government. I am here on quite a different mission. I'm not here to suggest how you might spend money, but to suggest how you might save it. And that is by not providing further funding for school-to-work programs.

As I noted on the editorial page of the New York Times this morning, these programs sound like a terrific idea. Schools should do a better job of preparing students for the work place. But as I also noted in the New York Times, the school-to-work programs that are being underwritten by a $2.3 billion Federal plan, these programs are now up and running in 37 States, and will soon likely to be in all 50. These programs are causing an enormous amount of parental consternation all across the country.

These programs are not targeted at vocational education. By Federal law, they include all students. What they're doing is assuming unwarranted authority over the students' lives. For example, a central thesis of school-to-work programs is that eighth graders should choose careers. And to help them along, schools administer tests of their interests and their personalities and make suggestions for them, which often have nothing to do with what the students might harbor as their own ambition.

I talked to a mother in Nevada whose daughter is an honor student and who wants to work for NASA. The school told her that she would be better in sanitation or interior design.

A Pennsylvania woman told me about a youngster in her neighborhood, this woman's name is Eunice Evans, told me about a boy in her neighborhood who wants to be a doctor, but the school told him he would be better off being a gas station attendant or truck driver. Eunice Evans pointing out that school-to-work programs typically lower, try to lower the aspirations of youngsters who want to undertake a high profile career, Eunice Evans said, who are these people who are playing God.

I think that is a very, very compelling question. Not only do school-to-work programs try to dictate job choices, they seek to inculcate attitudes, such as the belief that individual striving should be put aside in the name of group achievement. Having students work in teams is one way of fostering this thinking, and reinforcing it is group rating. A Texas Workforce Commission document suggests that teachers give every member of

a team the exam grade received by the lowest scoring member as a way of supporting and assisting the low achieving members.

You can see why these programs are making parents very angry. I set out in my op ed piece this morning many other aspects of these programs that I think are damaging our schools. But let me just emphasize one in particular. School-to-work programs typically say, all subjects have to be related to the work place. Everything a student studies should be related to the work place.

In Salada, Colorado, for example, the entire K-5 curriculum, reading, writing, social studies, arithmetic, for an entire year, recently, was related to careers in health care. A document that was handed out at a Kansas school-to-work gathering said, well, all right, you can teach things like literature, but it has to be literature that looks at different kinds of work and workers.

We have a long tradition in this country of using our schools to prepare citizens and not just workers. And we've always done this best when we have had students read literature and history, not for what they can say about the work place, but for what they offer as insights into the human condition.

The tradition of the liberal arts is being severely damaged by school-to-work. And it is that tradition that was so named because the word libertas in Latin means liberty, the liberal arts, have often long, and I think rightfully been seen, as a way of training people in the habits of independent thinking necessary in a democracy.

Well, all across the country, as I say, there are parents who are very upset about these programs. And it's really them I'm representing today, though I am at the American Enterprise Institute. I do hope that members of this subcommittee will listen closely to what these citizens have to say.

[The prepared statement of Lynne Chaney follows:]

[Pages 1089 - 1092--The official Committee record contains additional material here.]

Mr. Porter. Lynne, I'm very interested in what you have to say. Because I've always felt that when I was growing up, there was a tendency at a later age, maybe 17, to choose a career path. Our higher education system was organized in such a way to encourage early career path choices in concentrations on preparation for careers and not the broad, liberal education that I very much regret that I never got.

I spent my time studying business finance when I should have been studying languages or studying engineering subjects when I should have been studying philosophy and literature. I think you're absolutely right, that if that's what we're doing to our young people through this program, that's exactly what I don't want to see done. I think it is even more than citizenship, it is culture, it is a lifetime of expanding your mind instead of narrowing it.

That to me is the function of our education system more than any is to let people reach the level of their abilities and the extent of their dreams. If we aren't doing that, if

we're narrowing those choices and narrowing their focus, we're making terrible mistakes, I think.

Ms. Cheney. The New York Times, you know, editorial pages put their own titles on op ed pieces you write. They called my op ed piece this morning Limited Horizons, which I thought was a very, very good choice. Because I'm afraid that's what school-to-work programs are doing.

Businessmen do say, without question, that our schools need to do a better job. But when you ask them what they mean by that, and there was recently a poll done by Public Agenda, what they mean is, they want new employees out of the schools who can write effectively, and calculate.

The complaints that Public Agenda detailed in its poll were, you know, I asked this person to write a small report and he or she doesn't know about commas or paragraphs or grammar. It's the basic skills that businessmen want. I don't believe they really want this inculcation of attitudes and this stuff, early choice of careers.

Mr. Porter. I would add to that, I think the most important thing for developing in a child is imagination and understanding of the broad world out there and how to imagine and dream it in ways that may improve it.

Ms. Cheney. Well, I hope that my testimony will be of some use to you when it comes time to think about further funding of the School-to-Work Opportunities Act of 1994, or when the Careers Bill comes back to the House again, as I'm sure it will, after it goes to the Senate. Because both of these are part of the problem.

Mr. Porter. Mr. Hoyer.

Mr. Hoyer. Mr. Chairman, like you, I am a fan of, an admirer of, both the work of our former colleague Dick Cheney and of Lynne Cheney's work as well. Although I admire her work, I don't always agree with it. I think I may not agree with it in this instance, although clearly, I do agree that the anecdotes you use are not supportive of the program which you believe ought to be reduced, if not eliminated, in funding.

Without asking the specific questions, Lynne, I would very much like to follow up with you on the specifics. For instance, if Governor Bush knows that that's happening in Texas, I would presume he would want to look at that himself, or Governor Miller in Nevada, or Governor Ridge in Pennsylvania, in terms of Christine Jensen in Nevada and I thought it was a particularly egregious example that you used in Pennsylvania.

Because anecdotes can be very powerful, very frankly, I'd like to follow up and find out what the situation is, particularly if somebody wanted to be a doctor and was recommended to be a sanitation worker or truck driver or gas station attendant.

I don't know, I'm sure you probably read the autobiography of Malcolm X, in which Alex Haley cites that as a specific example of why Malcolm X was so hostile to the establishment community for most of his life, because of exactly an example like that. You're absolutely right. If these examples exist, they are wrong. I don't necessarily follow, therefore, that the program is wrong, because I'm not sure that I agree with you in total. Clearly, I think the business community does in fact want people who can think, which is what you're talking about,

as opposed to just do.

On the other hand, we are identified in America by what we do. What's your name, and the inevitable second question is, what do you do. So the objectives of school-to-work clearly are to give somebody an answer to that question. In welfare to work, which was universally supported, not necessarily the specifics, but of the concept that we expect each other to work to the extent possible, and carry our share of the load as citizens. One aspect of good citizenship is in fact working.

But I agree with you that the examples you use are examples which would offend, I think, most of us.

Ms. Cheney. They're not hard to find.

Mr. Hoyer. Including the dumbing down of giving the score to the lowest scorer in a team or group. I agree on teams and partnerships, all of that is good. But if we shoot for the lowest common denominator as opposed to the highest, we are making a mistake. I think your premise there is absolutely correct.

Ms. Cheney. It's been my observation, and I don't know if you would agree with this, either, but it's very hard for Governors when there is a block of Federal money that they can get not to take it. We went through this with Goals2000. Even Governor Allen, who was more opposed to Goals 2000 notions than perhaps anybody else in the Nation, any other Governor, ended up taking the money. What they do is try to do the least damage possible with it and the most good once they have it.

The school-to-work legislation is full of requirements that don't allow you to do the least damage possible. And what happens is this legislation empowers the Texas Education Agency, for example, whose ideas on education I think are often at cross purposes with the ideas of parents.

So even though the Governor is in charge of the State, once that money comes into the State, I'm afraid that people use it in all sorts of ways that philosophy the Governor might be in full accordance with.

Mr. Hoyer. In any event, I'd love to follow up with you on specific anecdotes.

Ms. Cheney. I'll put you in touch with these mothers and people.

Mr. Hoyer. Thank you very much.

Mr. Porter. Lynne, as always, your testimony has been very effective. And we very much appreciate your coming.

Ms. Cheney. Thank you very much for allowing me to come today.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Tuesday, February 3, 1998.

WITNESS

GORDON AMBACH, COUNCIL OF CHIEF STATE SCHOOL OFFICERS

Mr. Porter. Gordon Ambach, Executive Director, Council of Chief State School Officers, testifying in behalf of the

Council.

Mr. Ambach.

Mr. Ambach. Mr. Chairman, Representatives Bonilla, Northup and Hoyer, it is a privilege to be with you this morning and to take this opportunity, first and foremost, to applaud the actions that your committee has taken in the past two years on the investment in education. I say that on behalf of the State superintendents and commissioners across the country.

I wanted to say particularly, Mr. Chairman, to you, I applaud your leadership in the comprehensive school reform effort, which was first put into the appropriation for this year and which we hope will continue to thrive in the coming years.

Mr. Porter. We give most of the credit to Mr. Obey, but we work together on it.

Mr. Ambach. Well, it's a bipartisan effort, I know that, and that's what carried it through into realization.

Incidentally, we are working with the states to put that in place. It goes off on the first of July and we're very optimistic that it will be effective.

I'm very mindful of your admonitions about time, and also about the amounts of money or percent increases that we're requesting, all of us here today. The economy is strong. We hope it will stay strong. It is strong because of American enterprise and it's strong because we have the most productive work force in the world.

The educational system underpins that work force. So I am urging here your consideration of two aspects of education funding. The total education budget of course is very large. I can't cover it in a few moments. I want to select two parts of that.

The first is the innovation part of it, your new comprehensive school reform effort is a piece of that. Goals 2000 is a piece of that. Title VI is, the technology funds, the Eisenhower program. All of these together constitute the most important aspect of the Federal investment in changing the education system.

They total about $1.8 billion. Sounds like a lot of money. In terms of the $280 billion expenditure in this country, that's less than 1 percent. The President would move it up by around $300 million in this year. Frankly, we urge that you increase it a bit more.

We ought to be having about a 1 percent Federal R&D investment. And I think you could move to that in about two stages. That would be a half a billion or $500 million per year.

These programs work. We have provided you a copy of reports State by State. I know it's too long for submission into the record, but I can show you in that report in Illinois or in Texas or wherever it may be across the country, that the impact of these innovative Federal efforts is in fact working.

We have a substantial increase in mathematics scores in this country. All over the country, since 1990. It's because of systematic efforts, and these programs have helped.

I want to speak to one other general aspect of aid, and that is the equity or access mission of the Federal Government, going back to the Title I program in the mid-1960s, with the

IDEA program in the mid-1970s, certain aspects of the Perkins money. All of these efforts are designed to reach out to the students who have the least likelihood of success in their educational program.

Right now, we're serving only 60 percent of those children eligible under Title I. You recall that on the IDEA program, the initial intention was that the Federal Government would pick up about 40 percent of the cost. It's still stuck at around 10 percent of the cost. It's a big, big load.

But what is so important about access is that if we are indeed to have a population where all of our residents in fact have the skills for citizenship, develop their intellect, their creativity, as you just referred to, Mr. Chairman, not only have capability in the work force, but have capability for their families and for citizenship as a whole, we have to have virtually all students graduating from high school from here on out into this next century.

We're at about 85 percent at this point. The last 15 percent are the most costly, because they include those who are least likely to succeed.

With respect to these general programs, it is our urging that you be thinking about an increase at this point of something on the order of 15 percent in these programs. Again, it's a tall order. But if we're going to reach a virtual 100 percent, we have to move that direction.

Keep in mind that there will be 6 million more students in our country in 2005 than there are today. We're going up fairly close to a million a year on top of the issue of serving those who are not served right now.

Thank you for the opportunity to speak.

[The prepared statement of Gordon M. Ambach follows:]

[Pages 1097 - 1103--The official Committee record contains additional material here.]

Mr. Porter. Mr. Ambach, thank you.

I have to say about IDEA that we have done, I think, a very good job of moving up our commitment in that area over the last two years.

Mr. Ambach. You certainly have.

Mr. Porter. Why we are stuck on 10 percent is not quite accurate, we moved up to 10 percent I think, with $2 billion in new funding in that area over the last two years.

Mr. Ambach. You're correct.

Mr. Porter. But clearly, we want to try to do our best in that area to move that number closer to what was promised originally.

Let me ask a question, though, about comprehensive school reform. Because you're the first witness that has testified regarding that newly funded program. If we can't get additional dollars, additional new dollars for this program, is it your judgment that it is worthwhile to move existing Title I funding into this area?

In other words, take it away from the Title I and move it into comprehensive school reform? Obviously it's not going to

be a lot of money, but it's going to be some money.

Mr. Ambach. Mr. Chairman, I don't think you need to do that. The genius of the comprehensive school reform program is that coupled with Title I, it's leverage money. The money that's in the comprehensive school reform is intended tohelp, school by school, change the use of the resources that the school already has.

Now, you don't want to take away from Title I to make the change and then have to restore Title I to pick up the service.

Mr. Porter. Well, you don't want to, but what I'm saying is that we cannot serve anywhere near the demand that there is for comprehensive school reform funds, and if we can't get them from another source, is this a source that makes sense?

Mr. Ambach. Well, I would urge that you not do it in this next year. I would urge that you get the start on this program and see what type of a multiple effect that you have. If it's really working as effectively as we all hope, then the possibility of some transfer over or use of some potential growth. The President comes in with what, $400 million new in Title I. The use of a potential part of that growth in leveraging the funds, it seems to me, would probably make some sense.

I would urge that right now, we ought to have at least a year under our belts to see how effectively it's going to go. I'm very, very positive on this, and I can tell you that across the country, the States are as well.

Mr. Porter. Thank you, Mr. Ambach, for your testimony. We very much appreciate it.

Tuesday, February 3, 1998.

WITNESS

NATHANIAL H. MURDOCK, M.D., NATIONAL MEDICAL ASSOCIATION

Mr. Porter. Nathan H. Murdock, M.D., President, National Medical Association, testifying in behalf of the Association.

Dr. Murdock.

Dr. Murdock. Mr. Chairman and members of the subcommittee, thank you for the opportunity to present the views of the National Medical Association. I am honored to be the President of the National Medical Association. I am a practicing obstetrician-gynecologist in St. Louis.

Established in 1895, the National Medical Association is the largest organization representing African-American physicians. For biomedical research at the NIH, we recommend a 15 percent increase over fiscal year 1998.

The long term prospects for improving health disparities that exist among minorities in this country hinge on a strong Federal commitment to biomedical research. Yet, in order to fully realize the benefits of scientific investigation, much more needs to be done by NIH and policy makers to ensure that those who are suffering disproportionately are able to share in these advances.

We believe that if increased funding is made available to NIH, this subcommittee and the NIH leadership should target additional funding for those programs focusing upon improving

minority health. At a minimum, these programs should receive a proportionate increase in funding to that of the NIH overall.

Now that there is a greater recognition of improving minority health status as a national priority, we are asking this subcommittee to make a special commitment to minority health research. Specifically, we are recommending the establishment of a $1 billion research endowment program geared toward individuals and institutions with a commitment to solving the health problems of the minority communities.

For HRSA, the NMA recommendation is $306 million. Clearly, every responsible study ever conducted demonstrates that African-American physicians and other minorities are more likely to serve in medically underserved areas than their non-minority counterparts. Even though African-Americans represent approximately 12 percent of the U.S. population, only 2 to 3 percent of medical professionals in this country are African-American physicians and other health professionals.

If it is a national priority to narrow the health status gap that exists among minorities and non-minority populations, then it is imperative that we increase the number of minorities serving in health professions by supporting the health profession training programs.

For CDC, the recommendation is $2.8 billion. Health status challenges that exist in this country are magnified in underserved minority communities. The community based public health prevention activities supported by CDC represents the best Federal opportunities to begin solving these problems.

CDC has initiated several outreach programs targeted at reducing youth violence among minority populations and increasing infant immunization rates among African-Americans and other minority children. CDC is also working closely with the National Medical Association to initiate programs aimed at reducing tobacco consumption among minority populations.

The National Medical Association views the Healthy People 2000 initiative as one of great importance which, if appropriately applied, shows great promise to eliminate a variety of status disparities that exist among the Nation's citizens. We are concerned, however, that the approximately 300 objectives outlined in the initiative, the health status targets for African-Americans, are different, are lower than those for the general population.

We believe that the health status targets should be the same for all Americans. And that if the Nation can move toward achieving this goal, then it would seem natural for this subcommittee to provide the resources and program recommendations that we have outlined in this testimony.

Mr. Chairman, thank you for this subcommittee's support and the opportunity to present these views. Even though Congressman Stokes is not in the room at this time, I would be remiss if I did not applaud his leadership and dedication to improving the health status of minorities.

Also, Congressman Bonilla, we salute your leadership in the health professions training programs.

Thank you, Mr. Chairman.

[The prepared statement of Nathanial Murdock, M.D., follows:]

[Pages 1107 - 1112--The official Committee record contains additional material here.]

Mr. Porter. Both of those salutes are well earned. I might say that Lou Stokes has been a consistent and very strong advocate as you know for minority programs, and Mr. Bonilla, for the health professions. I've been dismayed to hear of Lou's intended retirement from Congress, because he's been so strong and such a strong member of this subcommittee. We're going to get the benefit of his service for the next year or so, but we're certainly going to miss him after that.

Dr. Murdock. Absolutely.

Mr. Porter. You mentioned a $1 billion program directed at minority health. My memory may be in error on this, but do I remember the President mentioning such a program in his State of the Union or not?

Dr. Murdock. I don't remember, sir.

Mr. Porter. Is this a program that the National Medical Association has conceived and promoted?

Dr. Murdock. I believe that's true.

Mr. Porter. I think it's subject to authorization, which means the committees would have to provide us law by which we can fund such a program. But in any case, we certainly will take your strong advocacy to heart in regards to minority health, and you can be assured that Mr. Stokes and Mr. Bonilla will be here to keep us on the right track.

Dr. Murdock. Thank you very much.

Mr. Porter. Dr. Murdock, we appreciate your testimony.

Tuesday, February 3, 1998.

WITNESS

MARGE DRUGAY, THE AMERICAN NURSES ASSOCIATION

Mr. Porter. Marge Drugay, N.D., R.N., C., Consultant on Healthy Aging, The American Nurses Association, testifying in behalf of the Association.

I have to say, Dr. Drugay, I don't think I've ever seen the single letter C after a person's name. Have I missed something?

Ms. Drugay. It indicates certification in a specialty.

Mr. Porter. Okay. I've learned something right there. Please proceed.

Ms. Drugay. Mr. Chairman and members of this distinguished subcommittee, may I be the first to wish you a good afternoon.

At the outset, I would like to thank and commend Congressman Porter and his staff for the fine work done on behalf of your constituents. As a past resident of the Tenth District for 27 years, I have had several occasions to contact your office on issues of concern both to myself and to the nursing profession. I have always received prompt and courteous attention, and I thank you for that.

I am a doctorally prepared clinical nurse specialist in private practice, serving as a consultant on issues of healthy aging. Today, however, I appear on behalf of the American

Nurses Association and its 53 constituent State and territorial nurses associations.

In my written testimony, I have addressed a number of programs that are important to both health care consumers and nurses, including programs related to work force health and safety. As an advocate for the economic and general welfare of registered nurses, ANA also recommends appropriate funding for the Department of Labor and related agencies that serve to ensure a safe and fair work place.

Today, however, I will focus my remarks on funding for nursing education and nursing research. ANA applauds the work of this subcommittee in recognizing the Nation's largest health care profession, and our importance in the delivery of health care. Ensuring that an adequate supply of well educated nurses is available reaffirms the need for continued funding in fiscal year 1999.

My specialty is gerontology. We are poised on the edge of a demographic explosion in aging. The current population of adults over the age of 65 is approximately 55 million people. By 2020, one in six Americans will be over 65. We are not prepared with enough qualified providers to meet the demands of this population, especially the fastest growing subset who are 85 years of age. Centenarians, those over 100 years of age, are now a commonplace entity.

As health care delivery continues to shift to non-hospital settings, the need for highly educated, scientifically prepared registered nurses will increase. Baccalaureate and higher degrees in nursing will be crucial in providing front line care, education and preventive services in the 21st century.

Doctorally prepared nurses are required to conduct nursing research and for faculty positions to prepare our future nurses. To complicate matters further, an aging R.N. work force will also fuel the increased demand for R.N.s. According to the division of nursing, in 1996, the average age of nurses was 44, and only 9 percent of the Nation's two and a half million registered nurses were under the age of 30.

Data from the U.S. Bureau of Labor Statistics shows employment of R.N.s will increase faster than the average for all occupations through 2006. The recent trend to reduce R.N. staffs and increase the use of unlicensed assistive personnel has proved unsatisfactory, producing poor outcomes and prompting more hospitals to boost R.N. recruitment.

Federal support for nursing education in Title VIII is essential. This is the only Federal money earmarked for nursing education. Funding supports curriculum development and other programs to expand the focus of nursing education to non-hospital settings and greater health promotion efforts. Funding also supports greater numbers of minority nurses who provide culturally competent, linguistically appropriate health care services to underserved populations.

Today, we are requesting fiscal year 1999 funding of $70.8 million for the programs funded under the Nurse Education Act. This is an 8 percent increase over current funding.

Our second priority is funding for the National Institute of Nursing Research at NIH. Again, we applaud this subcommittee's commitment to advancing behavioral science research. Nursing research is an integral part of nursing care,

as indicated by Dr. Hinshaw. And it has shown that health promotion is effective.

In Illinois, we developed a successful wellness model geriatric outreach program, based on the HHS initiatives, Healthy People 2000, and put prevention into practice. We support the Administration's proposed funding level of $68.3 million for this program, and would recommend funding of 15 percent over the fiscal year 1998 level of $63.5 million, bearing in mind the Chair's comments.

We appreciate the opportunity to comment on funding for nursing education and nursing research programs. We thank you for your continued support, with a special thanks to Congressman Bonilla, and look forward to working together as you go through the appropriations process.

Thank you.

[The prepared statement of Marge Drugay follows:]

[Pages 1116 - 1125--The official Committee record contains additional material here.]

Mr. Porter. Dr. Drugay, did you say you were a former Tenth District resident?

Ms. Drugay. Yes.

Mr. Porter. Where have you gone?

Ms. Drugay. I am currently a Fifth District resident in Arizona.

Mr. Porter. Arizona?

Ms. Drugay. Yes, Tucson.

Mr. Porter. You left our wonderful State of Illinois?

Ms. Drugay. My husband retired, I had to go along with him.

Mr. Porter. Well, we'll forgive you in that case. Thank you very much for your good testimony, and we'll do the best that we can to meet the needs.

Tuesday, February 3, 1998.

WITNESS

DOUGLAS SCHACKE, NATIONAL ASSOCIATION OF INDEPENDENT COLLEGES AND UNIVERSITIES

Mr. Porter. Douglas Schacke, Dean of Admissions and Financial Aid, Barat College, Lake Forest, Illinois, testifying on behalf of the National Association of Independent Colleges and Universities.

Dean Schacke, you are, I hope, a constituent of mine. I have an honorary degree from your institution, as you are probably aware, and I will listen very intently to what you have to say.

Mr. Schacke. Great, thank you.

I, too, Mr. Porter, would like to thank you for all the support that both you and your staff have offered to us at Barat over the years.

My name is Doug Schacke, I'm Dean of Admissions and Financial Aid at Barat College in Lake Forest, Illinois. Thank

you for this opportunity today to speak with you on behalf of the important issue of funding student aid.

According to the 1990 census, 13.7 percent of the population of this country had at least a bachelor's degree. That's 13.7 percent of the population. I don't know about you, but most of my professional and personal circles that I travel in, it's easy to take higher education for granted. Most of the people that I come into contact with have at least a bachelor's degree, if not a masters or a Ph.D.

Less than 14 percent of this population in 1990 had a bachelor's degree. I find this figure astonishing.

You probably have heard the phrase, knowledge equals power. In many ways, this phrase is very true. Higher education is key to keeping our Nation prosperous and successful. I am here today to talk about the importance of federally funded programs for higher education.

I've been involved in student aid for seven years. Barat College is a strong liberal arts college serving 800 students, mostly from the surrounding communities. Barat has a strong tradition of educating students who come from diverse backgrounds and experiences.

Over 20 percent of our students are from minority populations. In addition, 38 percent of the student body is over the age of 25. Most of these individuals have been in the work force for some time and realized that college education is a necessary tool for moving ahead in their professions.

With this in mind, our curricula is designed to provide both theoretical knowledge and practical experience. Our tuition is at about the national average for private colleges, $12,570. I'm testifying today on behalf of NAICU, the National Association of Independent Colleges and Universities. This organization represents a broad array of over 900 of the Nation's private, non-profit colleges and universities.

First, I would like to thank you for the strong support you have shown for student aid in higher education. In particular, I would like to highlight the increase you provided last year for the Supplemental Educational Opportunity Grant program and the increase in the Pell maximum. This increase in SEOG was the first in five years, and the increase in the Pell grant was the largest in nearly two decades.

The current student aid programs play a critical role in our Nation's ability to educate its citizens. These programs are often referred to as patchwork, but I can tell you from first-hand experience that they work together to provide assistance to many students.

For example, without a combination of Federal, State and institutional aid, a student like Roberto Silva would not be able to achieve his dream of becoming a high school teacher. Growing up in Chicago and attending public schools, Roberto has experienced first-hand the importance of education and the challenges that inner city students face.

Because of this, Roberto has dedicated himself to becoming a high school social studies teacher. Not only does he desire a career in teaching, he is passionate about serving as a role model for disadvantaged urban youth. His goal is to show young people that they have options and how to plan for their futures.

However, coming from a single parent household with no income to support his quest for higher education, Roberto knows that financing would determine whether or not his dream would become a reality. Without a combination of the maximum Pell Grant, SEOG, Federal work study, or Perkins loan, a state grant and additional assistance from the college, he would not be a junior in college today, preparing to student teach next year. If even one form of these aids were reduced or eliminated, his ability to continue in college would be in serious jeopardy.

Another student I want to tell you quickly about is named Shane Abbott. Shane came to Barat from Texas. When he was a senior in a public high school in Dallas, Texas, he was deciding where to go. He found out about us because we had two programs that were of strong interest to him. We have a strong theater major, which is his intended field of pursuit. We also have a strong program for college capable students who have learning disabilities.

Because he came from a disadvantaged high school setting, he wasn't diagnosed with learning disability until the end of his junior year. Our program seemed like it was the perfect fit for him. However, when he filled out his FSFA, he realized that his estimated family contribution was zero. Meaning that they had no funds to fund his quest for higher education.

Now, the difference between Shane and the previous student that I mentioned, Roberto, is that Shane didn't come to Barat from the State of Illinois. Therefore, he wasn't eligible for the generous state grant program of at least $4,000. We had to work with Shane very closely to see what we could do as an institution to help support his quest for higher education.

Well, it worked out that Shane wasn't able to come to us right away. Shane took two years off, worked in a factory, saved some money and was able to start Barat last year. He current is a sophomore.

Instead of going through each of the different grant programs and loan programs, I want to highlight one specific one, and that's the Federal work study program. I urge you to provide $900 million as requested by the President. Work study is a cornerstone self-help student aid program. Students are able to earn funds to help pay their way through college.

This investment in student aid is an investment in our Nation's future. Our preparation for the 21st century hinges upon our attention to educating our citizens.

I thank you, and I welcome any questions.

[The prepared statement of Douglas Schacke follows:]

[Pages 1129 - 1135--The official Committee record contains additional material here.]

Mr. Porter. Dean Schacke, can I go back to your 13.9 percent figure for bachelor's degrees? That's----

Mr. Schacke. Yes, 13.7.

Mr. Porter. That's 13.7 percent of the whole population?

Mr. Schacke. No, that's 13.7 percent of the population that would be of the age to at least have a bachelor's degree. That's over 21.

Mr. Porter. That does seem unusually low, and includes obviously all advanced degrees beyond that?

Mr. Schacke. Exactly.

Mr. Porter. The President initially considered zeroing out the Perkins capital contribution to fund an increase in SEOGs to $679 million. In the end, the President put $60 million into a Perkins increase and reduced SEOGs to $619 million. If you had to make that decisions, which would you put at the higher priority?

Mr. Schacke. I would put the SEOG at the higher priority.

Mr. Porter. You would?

Mr. Schacke. Yes.

Mr. Porter. Why?

Mr. Schacke. I've found that with most of our students, the SEOG is much more critical in supplementing their aid package than the Perkins loan is. It has, the combination of all together, SEOG stands out as more critical in the whole package.

Mr. Porter. Is Barat under the direct loan program?

Mr. Schacke. Yes, we are.

Mr. Porter. And you're finding that satisfactory?

Mr. Schacke. Yes, it has certainly some challenges administering it on our side, but it has certainly increased the time in which students receive the funding. So we have, the students have definitely seen a benefit from that.

Mr. Porter. Dean Schacke, thank you for coming to testify. We very much appreciate it.

Mr. Schacke. Thank you.

Tuesday, February 3, 1998.

WITNESS

EUGENE LEHRMANN, AMERICAN ASSOCIATION OF RETIRED PERSONS

Mr. Porter. Eugene Lehrmann, Immediate Past President, American Association of Retired Persons, testifying in behalf of the Association.

Mr. Lehrmann.

Mr. Lehrmann. Good afternoon, Mr. Chairman. I'm Gene Lehrmann, the Immediate Past President of the American Association of Retired Persons, from Madison, Wisconsin. Thank you for this opportunity to comment on various programs which benefit older Americans, especially low income and minority elderly.

Of particular significance in this regard, the Older Americans Act and Low Income Home Energy Assistance Program, better known as LIHEAP, these initiatives play key roles in helping needy Americans preserve their dignity and independence. Since its enactment over 30 years ago, the Older Americans Act has enabled millions of older citizens, especially those with disabilities, to remain independent and productive.

Many of these individuals would have ended up in expensive institutional settings were it not for the home and community based services provided by this landmark legislation. At a minimum, the Association recommends for an inflation adjustment

next year for OAA programs. We applaud Congress for providing increases this year in many of the programs.

Among other things, the extra funds mean nutritional meals for more seniors, particularly those who are isolated and frail. The home delivered meals program is very often the only human contact some of these persons have in a given day. And their lives are enriched by these visits in ways which cannot always be measured.

The increase in funds this year will also provide additional supportive services. These include transportation for doctor and pharmacy visits, homemaker assistance and legal counseling. A critical part of the Older Americans Act is the Senior Community Service Employment Program, known as SCSEP.

As one of the national sponsors of this activity, the Association has first-hand knowledge regarding its effectiveness. SCSEP has made a real difference in the lives of many unemployed, low income older Americans by providing part time jobs which are useful in community service. Many of the nutrition programs and other services for seniors, as well as important programs serving the broader community, such as library services and day care centers, are dependent on work provided by persons through SCSEP.

Compared with younger workers, once unemployed, older workers tend to be jobless longer and are likely to earn less when and if they are hired.

With regard to the Low Income Home Energy Assistance Program, Mr. Chairman, at a minimum the Association strongly urges at least $1.2 billion in regular funds next year, an amount equal to the total spending level in fiscal year 1997. Because this program is advance funded, Congress provided $1.1 billion for fiscal year 1999 in the fiscal year 1998 appropriation. We are recommending an increase of $115 million over that level for the coming fiscal year.

We also recommend the same amount for the fiscal year 2000 advance appropriation. LIHEAP is important to all of its beneficiaries. But none more so than the low income older person, housing, health care and energy.

I want to thank you for this opportunity to present our views regarding appropriations next year for programs which benefit older Americans.

[The prepared statement of Gene Lehrmann follows:]

[Pages 1138 - 1147--The official Committee record contains additional material here.]

Mr. Porter. Mr. Lehrmann, thank you for your testimony. Just out of curiosity, what did you do before you became President of AARP?

Mr. Lehrmann. I was an educator in Wisconsin. When I retired I was the State Director of Vocational Education.

Mr. Porter. So you're originally from Madison? You spent a good deal of your adult life there?

Mr. Lehrmann. Yes. I spent, actually now, it's 30 years of my life in Madison. Other than that, I was in Kenosha, Wisconsin for nine years. And I taught in Wassau, Wisconsin,

for 11 years.

Mr. Porter. Kenosha's not far from my district. I go right up to the Wisconsin line.

Mr. Lehrmann. I noticed that, sir.

Mr. Porter. Madison is certainly a wonderful town to live in.

Mr. Lehrmann. It is, it's a lovely city.

Mr. Porter. Regarding LIHEAP, you're probably aware that I have a great problem with the program. Because I think while it meets a need, the need is one related to poverty more than it is to energy costs. Because energy costs have gone way down since the program was enacted. And the rationale for the program has, in my judgment, completely disappeared.

The need is still there, however, and you've got people who need the help. I wish they would restructure the program in such a way that it is aimed at the right target, and not hang it on the I think hook of energy prices, which are no longer the serious problem they were at the time of the Arab oil embargo.

Otherwise, I think it's obviously a place for people who need help.

Mr. Lehrmann. No question, Congressman. It follows low income, it follows poverty. And you know as I do, living in the northern part of the country, 20 degrees below zero at night takes a lot of energy. But your point is well taken. I think funding sometimes directs how programs develop and this may have been the case.

Mr. Porter. To me, it's an evidence of the Federal Government's inability to change and eliminate and restructure programs whose rationale has long since disappeared. I think it kind of undermines the support for the need that I readily admit is very much there.

Obviously the mechanism of providing help by paying on energy costs is probably a very good one. It's simply, the rationale's not an accurate one.

Mr. Lehrmann, thank you very much for coming to testify. We very much appreciate it.

Mr. Lehrmann. Thank you very much, Congressman. My pleasure to be here.

Tuesday, February 3, 1998.

WITNESS

JAVIER SALAZAR, THE ADAP WORKING GROUP

Mr. Porter. Javier Salazar, member of the ADAP Working Group, testifying in behalf of the Working Group.

Mr. Salazar.

Mr. Salazar. Good afternoon. My name is Javier Salazar and I'm testifying on behalf of the Aids Drug Assistance Program Working Group, where I'm an active participant representing AIDS Action Council here in Washington.

I'd like to start by thanking you, Mr. Chairman, and the rest of the committee, for the extraordinary leadership that you've shown in support of all AIDS programs, as well as the AIDS drug assistance program. I also want to thank you on

behalf of the tens of thousands of people living with HIV and AIDS nationwide, their families and their friends.

The work of this committee has played a tremendous role in the realization of the incredible news that we hear daily about the strides that we as a Nation are making in the fight against HIV disease. You've seen the headlines, the statistics about the dramatic drops in AIDS deaths and about the potential of the new, powerful therapies.

Just today, today's Washington Post reports a stunning 44 percent in AIDS deaths in the first half of last year.

But I want to tell you about the fantastic news that these new therapies have brought in my life, and how fortunate I was not only to have had access to them, but to when and how I was able to take them. Originally from San Antonio, I'm the son of proud Mexican immigrants. I came to Washington after graduating from the University of Notre Dame.

Once here, I had the privilege of working for Senators Lloyd Bentsen and Kruger from my home State of Texas. I was the young, ambitious face that so characterizes Capitol Hill. I was that face that you see in your office and in the hallways.

When things could not have been better, I tested positive for HIV. I was 24 then. My T-cell count was 349, and I thought that all hope was lost. But I had other things to worry about. Not only was I faced with the tragedy of my own infection, but with the tragedy that my partner, Ron Mallon, whom I loved dearly, was dying of AIDS.

At a time when I should have been worrying about furthering my career, achieving my goals, I was saying goodbye to Ron in a hospital here in Georgetown. Most would accept that the death of a partner is something that people deal with later in life. I was not that lucky. Ron died on August 8th, 1995, a week after my 27th birthday. My T-cell level had now fallen to 210, just 10 above an AIDS diagnosis.

A month after, I learned about combination therapy with protease inhibitors. I joined a clinical trial and began to take the potent combination of potent antivirals, including a protease inhibitor. I've been on the very same combinationfor over two years. My viral load, the measure of active virus in my bloodstream, has been undetectable for over two years. My T-cells have tripled, and at last count, they were well over 700. I'm 29 now.

What is so exceptional about that? Well, once I thought that I would surely develop AIDS soon and not even live to see the age of 40, or even 35. Life seems more hopeful now. Why? Because I got the drugs, the medical care, services and the support that is essential to taking these drugs successfully.

Even more, I started taking these drugs in combination. I had never put an anti-HIV drug in my body. I was what is referred to now as treatment naive. I took a combination of drugs from the very beginning, and my viral load was suppressed below detection.

This strategy is now the driving force behind the recently compiled NIH-PHS guidelines for the treatment of HIV disease. My friends have started calling me the living guidelines made real, real hope. But along with this bittersweet pill, I can't help to think if only, if only my partner would have had the chance that I got. Maybe he could be alive today. If only more people could get the drugs and the care that they need, they

could share in the hope that I am so fortunate to have today.

That's where the work of this committee is so important. Every person must have the opportunity to access these helpful therapies early and in accordance with the new treatment guidelines. It's critical that individuals have access to the entire arsenal of drugs and not have to suffer from the disastrous implications that may occur as a result of only having access to substandard anti-viral therapy and care.

This committee has shown great commitment to the needs of people living with AIDS. I ask you to continue and strengthen your commitment by increasing funding for ADAP and to providing the necessary resources to provide the medical and enabling services critical to the success of drug therapy.

Thank you for this opportunity, and thanks for letting me share my story. There's a written statement for the record.

[The prepared statement of Javier Salazar follows:]

[Pages 1151 - 1158--The official Committee record contains additional material here.]

Mr. Porter. Thank you, Mr. Salazar. Could I ask a question? Is there side effects to these drugs?

Mr. Salazar. Yes. I myself have experienced two bouts of kidney stones. I don't know if you have ever had a kidney stone.

Mr. Porter. Very painful, I understand.

Mr. Salazar. So yes, I've had those side effects. I have general kind of fatigue. I felt better when I wasn't on them, to be honest with you, physically. But yes, a great deal of side effects.

Mr. Porter. Well, we realize how expensive they are and how we need to provide them to people who are at obviously serious risk. We're very encouraged that the President has placed this this year at a very high priority in his budget, which gives us a lot of support for providing those kinds of resources.

Mr. Salazar. You've led the way.

Mr. Porter. So I think we're all on the right track now, and we appreciate your testimony and we'll do our best to continue providing support for the ADAP program.

Mr. Salazar. Thank you.

Mr. Porter. Thank you.

Tuesday, February 3, 1998.

WITNESS

ARTHUR L. DAY, M.D., AMERICAN ASSOCIATION OF NEUROLOGICAL SURGEONS AND THE CONGRESS OF NEUROLOGICAL SURGEONS

Mr. Porter. Arthur L. Day, M.D., James and Newton Eblen Eminent Scholar and Professor of Neurosurgery at the University of Florida, testifying in behalf of the American Association of Neurological Surgeons and the Congress of Neurological Surgeons.

Dr. Day. Thank you, Mr. Chairman. I am, as you mentioned, a

professor of neurological surgery at the University of Florida. I appear here today on behalf of the American Association of Neurological Surgeons, the AANS, and the Congress of Neurological Surgeons, the CNS.

We wish to thank you for the opportunity to comment on the fiscal year 1999 neuroscience agenda. Spinal disorders, vascular diseases of the brain and genetic disorders represent the three most common afflictions to the central nervous system. With these conditions in mind, we urge the subcommittee to direct its funding to five areas of research for the upcoming year.

The first is head and spinal cord injury. Trauma to the brain and spinal cord is the leading cause of death and disability among children and young adults. The direct and indirect costs of traumatic spinal cord injuries alone are estimated to be over $7 billion annually.

New drugs can reduce the amount of the brain and spinal cord damage produced by these injuries. Functional recovery can also be enhanced by prompt therapeutic interventions.

Ultimately, the ability to restore function of injured brain or spinal cord is the key to all types of central nervous system diseases. We believe that the basic research targeted at this goal should be a major priority for the following year.

Number two, stroke. Stroke is the third leading cause of death in the United States. It's also the leading cause of long term disability. Every year, 500,000 new cases are diagnosed in our country at an estimated cost of $30 billion.

Aggressive medical treatments before or early after the onset of stroke symptoms can now significantly improve outcomes. Recently, the concept of brain attack, similar to the implications of a heart attack, has gained the support of many neurologists and neurosurgeons across this country. The major thrust of brain attack programs is an early diagnosis, a rapid restoration of blood flow to areas of the brain lacking circulation, and pharmacological protection of brain cells from irreversible damage.

These therapeutic actions must be carried out rapidly within a window of opportunity before irreversible brain damage occurs. We are convinced that your continued support for these programs will lead to a substantial life saving and function saving progress in this area.

Number three, molecular treatment of brain tumors and other disorders of the nervous system. Brain tumors represent the third leading cause of cancer deaths in middle aged males. Tumors of the nervous system are the second leading cause of cancer deaths among children.

Every year, more than 10 percent of the 400,000 new cancer patients in this country see their disease spread to the brain or spinal cord. In many such patients, the nervous system tumor constitutes the single most immediate threat to their life and function.

The application of molecular biology and its techniques to the central nervous system have revolutionized our understanding of how brain tumors grow and spread. Therapeutic drugs and genetic material can now be directly injected into specific regions of the brain to kill tumor cells, while other parts of the brain and body are shielded from injury.

Disorders such as Parkinson's disease, Tay-Sachs, Huntington's disease and Alzheimer's dementia can be similarly treated with such magic bullets, and can reduce the $100 billion annual cost of these diseases. Your continued support can help identify the full range of genetic abnormalities that underlie these crippling nervous system disorders.

Number four, research into spinal disorders. Disorders of the spinal cord, the spinal nerve roots and the bony spine are common causes of pain and disability in our country.Each year, 15 to 20 percent of the population will have an episode of back pain. And during their lifetime, about 70 percent of U.S. citizens have an episode of serious back or leg pain caused by diseases of the spine.

Currently, back and leg pain are the second most common reason for physician visits in this country. Recent progress in basic neuroscience research has markedly enhanced our understanding of basic pain mechanisms and how the spinal cord controls movement and integrates sensation. Further research that identifies these mechanisms that cause pain and loss of function whenever the spinal cord or nerve roots are injured can help allow the identification of more effective methodology and less invasive treatments in the relief of such symptoms.

It is also clear that some patients with serious spinal disorders can only be helped with surgery. Clinical and outcome research in this area could help physicians to more expeditiously evaluate patients with spinal disease and then more appropriately select patients for operative treatment, thus limiting the patient's time of anguish before definitive therapy is performed.

Number five, and finally, outcomes research. Technology is now driving the contemporary treatment of neurologic disorders at an unprecedented degree. The cost of these new technologies can be easily justified if the benefits of decreased suffering and additional years of useful survival outweigh the amortized costs of such treatments.

Outcomes research can do much to guide patients, physicians and policy makers in therapeutic decision making and resource allocation. We urge you to provide funds to the Agency of Health Care Policy and Research to improve the methodology for outcomes research in neurological disorders, and to support pilot studies in the treatment of stroke, brain tumors and degenerative spine disorders.

Mr. Chairman, as we approach the final year of the decade of the brain, and now the new millennium, the AANS and the CNS hope that the Congress will continue its commitment to biological research for nervous system disorders. These funding priorities are costly but can have a major impact on the quality of life for our citizens.

Thank you for your considerations.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

[The prepared statement of Arthur L. Day, M.D., follows:]

[Pages 1162 - 1166--The official Committee record contains additional material here.]

Mr. Porter. Dr. Day, thank you for your testimony.

I have to say that number four had a particular resonance with me, as a year ago, sitting in this chair, I had the most horrific back pain that went on for more than four months. I guess I fall in that 80 percent category of having experienced it.

All of these are very important areas for us to focus our attention on, and I can assure you we're going to do our very best to provide the resources that are needed.

Dr. Day. Thank you.

Mr. Porter. Thank you for coming to testify.

That concludes our witness list for this morning's session. We stand in recess until 2:00 p.m.

Afternoon Session

Mr. Porter. The subcommittee will come to order.

We continue, this is our sixth session with public witnesses, and we now have had the benefit of the testimony of 100 witnesses. And we have about 100 to go. What we're attempting to do, obviously, is to start early in the session in order to avoid interruptions from recorded votes. We will be able to do that today and hopefully not have too many on Wednesday and Thursday.

Our attempt, obviously, is to allow as many public witnesses to testify as possible. We are oversubscribed, but we're doing our best to accommodate as many as we possibly can. We would appreciate all witnesses observing the time limits that allow additional numbers to testify.

Tuesday, February 3, 1998.

WITNESSES

KATHY HUNTER, INTERNATIONAL RETT SYNDROME ASSOCIATION
DEAN HUNTER (SON)

Mr. Porter. Our first witness is Kathy Hunter, the Founder and President of International Rett Syndrome Association, accompanied by Dean Hunter, her son, testifying in behalf of the Association.

Mr. Hoyer.

Mr. Hoyer. If I might, I want to welcome Kathy Hunter. As you know, she has testified, Kathy, when's the first time you testified, about eight, nine, ten years ago?

Ms. Hunter. About 1986.

Mr. Hoyer. So 11 years ago, 12 years ago. And she has done an extraordinary job. Rett Syndrome, as I'm sure some of you know, is a neurological disease that impacts after about 12 to 18 months of development, so that the child, it's almost exclusively female children. Do we have any male children that we've identified? Two. But exclusively female children that are impacted.

The way I got involved in this, I go to church with a Rett Syndrome child, Christy Smith, who is now I guess 25 years of

age. So I've known her since she was I guess 8 or 9. She's an extraordinarily warm and loving individual. She is now partially institutionalized and partially at home with the Smiths.

Stacy, who is your sister, is an extraordinary young woman herself, and has been here. I see Stacy's not here this year. You mentioned this morning somebody who had a son and the courage they show and the commitment they show and the difference they make. Kathy Hunter is one of those people, Mr. Chairman.

Mr. Porter. We all agree with that. Thank you, Mr. Hoyer.

Mr. Dickey.

Mr. Dickey. Mr. Chairman, I'd like to state for this side of the aisle that we're very pleased that you go to church, Mr. Hoyer. [Laughter.]

Mr. Hoyer. I want to state from this side of the aisle, when I do, I pray for the other side of the aisle. [Laughter.]

Mr. Porter. Especially for Arkansas.

Ms. Hunter, we're not charging your time against those comments.

Ms. Hunter. Thank you, Mr. Chairman, Mr. Hoyer and distinguished members of this committee. It is my greatest honor to appear before you once again as Founder and President of the International Rett Syndrome Association.

I speak on behalf of thousands of girls and their families whose lives have been changed forever by Rett Syndrome. I must admit that I wish this committee had compelling magic powers and could make even the bravest dreams come true. If that were so, I would rejoice to never have to come before you again.

As Helen Keller once said, although the world is full of suffering, it is full also of the overcoming of it. We applaud your enthusiastic support for the National Institutes of Health and its dedication to the health and welfare of Americans, particularly during these difficult fiscal times. We are most grateful for your past support of research into Rett Syndrome and other neurological disorders, and ask for your vigorous continued support for the national research effort in fiscal year 1999.

Imagine for a moment a wonderful baby girl as pink and round as a cherub and as precious as a porcelain doll. Picture her first steps and delightful babble as she takes in the world around her with wonder and laughing abandon. See her squeal with delight as she plays with her favorite toys. Imagine the hopes and dreams for a fulfilling life that lie ahead.

Then imagine what it must be like to witness her laughter turn suddenly to frightening screams, her babble to deafening silence, her toddling steps to stillness, her recognition and understanding to utter confusion. Think of what it would be like to watch one seizure after another and the development of painful stiffening joints and curvature of the spine. Think of what it must be like to watch her grow, yet never grow up.

Imagine that no one knows how or why it happened, and no one knows how to make her better. Finally, imagine that she is your child. It is happening somewhere in America just as I speak. Families watch in fear and disbelief as their little girl slips away from their reach.

As one mother wrote, the children are a constant reminder

that this can happen to anyone. When you see a child with Rett Syndrome, you come face to face with the fact that you can do everything right and still have a child with severe multiple disabilities.

Another mother writes to express the painful yet valuable growth process it takes to cope and gain perspective. There is added dimension to our character, a sense of strength to adjust and accept, a more tender heart to care deeply and lovingly, to love so unconditionally. Jen was the most beautiful baby I ever saw. I would gaze upon her beauty, relish in the thoughts and dreams of motherhood and life with this beautiful daughter.

Girls with Rett Syndrome cannot talk or use their hands, and many do not walk. They need help for every aspect of daily living, bathing, dressing, feeding, toileting, communicating. Yet they began their lives with great promise.

It is only through recent research that we have come to more clearly understand their true potential. Dr. David Koppenhaver, researcher at Duke University, said that these girls are complicated, but we are convinced that they are teachable. Until now, girls with Rett Syndrome have been classified as severely to profoundly mentally retarded and unteachable, spending their lives trapped in bodies that will not allow them to show us what they understand.

What a revelation to find that with the use of augmentative communication techniques, we can expect them to learn. Hope is alive.

My daughter Stacy, now 23, was the first child diagnosed with Rett Syndrome in the United States in 1984. My son Dean joins me today as a witness to the life story of Rett Syndrome. He was five years old when Stacy was born. He grew up with the many challenges our family faced, but only recognized the full depth of our anguish when he recently became a father himself.

We are fortunate that the most striking feature his beautiful son inherited are his deep blue eyes. But with each new child begin in our family, we must begin a tormenting cycle of worry again, wondering whether the second year of life will bring joy or tragedy.

One of the greatest barriers to genetic studies has been a relatively small number of families with more than one affected child. A recent collection of data on several new families with more than one child and two male children with Rett Syndrome have contributed revealing clues to the mystery. We're very grateful that in June of this last year NICHD sponsored a study group on the genetic basis of Rett Syndrome, at which time a number of innovative research strategies using advanced genetics techniques, were shared.

In response, the International Rett Syndrome Association has made a commitment to fund $94,000 in 1998 to the newly established Rett Syndrome Consortium, and continues to fund seed grants and recruit talented researchers to the field, in addition to identifying new cases and encouraging research participation.

Exciting work includes the development of a mouse model showing definite alterations in receptors in regions of the brain that appear to function abnormally in Rett Syndrome. On the genetic map, we have located the state and city and have narrowed the research to finding the right street.

The study of living brain cells and nasal biopsies has shown that these cells are inactivated, not dying as previously thought. This work may provide a scientific marker or prenatal test for Rett Syndrome.

Other promising findings may lead not only to the scientific marker but to rational treatment approaches and a potential cure. Autopsy studies have revealed abnormalities in specific areas of the brain which correlate to the clinical problems seen in Rett Syndrome, such as movement, equilibrium, cognition, awareness, behavior, memory and emotion. The heart has been shown to possess an image or conduction system thought to parallel what is seen in the brain and possibly responsible for the sudden, unexpected death in sleep that is seen in Rett Syndrome. That is the largest single cause of death, sudden death in sleep.

These studies lead to the speculation that growth factors, which are responsible for maturation of the heart and central nervous system, are altered, thus leading to the developmental arrest which is seen. We are most grateful to the subcommittee for their earnest consideration of this request for increased funding for all neurological disorders, especially as we come to the close of this decade of the brain.

The intensive search for genes related to developmental delay, mental retardation and growth failure will undoubtedly lead to findings in a number of other disorders which affect many thousands of Americans. As we stand on the threshold of discovery, we urge you to provide funding for studies which may have a high risk for failure, but which at the same time may yield important new information which increases our understanding of Rett Syndrome and other neurological disorders.

We heartily support the recommendations of the Friends of NICHD and the National Committee for NINDS Funding, and look forward to the progress to come that will bring about a better life for our daughters.

In closing, I want to quote Margaret Mead, who said, never doubt that a small group of thoughtful, committed citizens can change the world. Indeed, it is the only thing that ever has.

Just as our daughters look to us for help, we look to you for hope. Thank you.

[The prepared statement of Kathy Hunter follows:]

[Pages 1171 - 1176--The official Committee record contains additional material here.]

Mr. Porter. Well, Kathy, you're one of those band of dedicated individuals. You've been here and you've never given up for a moment, and you are making a tremendous difference.

We appreciate the leadership and commitment that you've shown, and we're going to do our best to provide the funds so we can get some breakthroughs and prevent this disease from affecting further human beings. Thank you for being here, and thank your son for being here as well.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives

was not received from this witness or from an entity represented by this witness.]

Tuesday, February 3, 1998.

WITNESS

DORR DEARBORN, M.D., CASE WESTERN RESERVE UNIVERSITY AND RAINBOW BABIES AND CHILDREN'S HOSPITALS OF CLEVELAND
TERRY ALLEN

Mr. Porter. Dr. Dorr Dearborn, Associate Professor of Pediatrics, Case Western Reserve University, representing the University and the Rainbow Babies and Children's Hospitals of Cleveland.

Mr. Stokes.

Mr. Stokes. Thank you, Mr. Chairman.

Mr. Chairman, it's a pleasure for me to welcome before our subcommittee today Dr. Dorr Dearborn, who as you've stated is Associate Professor of Pediatrics at Case Western University. He today is representing both Case Western Reserve University and Rainbow Babies and Children's Hospitals of Cleveland.

Accompanying him this morning is Mr. Terry Allen, who represents the Cuyahoga County Board of Health. I'd like to extend a warm welcome to both of you. It's a pleasure to have you here.

Thank you, Mr. Chairman.

Dr. Dearborn. Mr. Chairman, Congressman Stokes and other members of the subcommittee, I am Dorr Dearborn, a pediatrician at Case Western Reserve University School of Medicine. I specialize in children's lung diseases.

We thank you for allowing us to tell you today about an outbreak of pulmonary hemorrhage that is killing infants in the Cleveland area and around the country. A previously rare disorder, acute pulmonary hemorrhage, has been diagnosed in38 infants in the Cleveland area in the past 5 years. This serious disorder causes infants to cough up blood and usually requires intensive care measures to save them.

Fourteen of these infants have died, including nine originally thought to be sudden infant death syndrome. Thirty infants were African-American, all of whom lived in a limited geographic area of western metropolitan Cleveland, an area of older housing stock. This area corresponds directly with Congressman Stokes' district.

An investigation of this outbreak led by the CDC has linked this disease to exposure to a toxic mold called Stachybotrys, which was found in the infants' homes. This mold requires water-saturated wood products to grow, and appears to have occurred secondary to chronic basement flooding or from chronic plumbing or maintenance problems. Once the source of water damage is corrected, the mold can sometimes be removed by a bleach solution. However, more extensive abatement is often necessary.

Stachybotrys, while not a common mold, is know to have a wide distribution. We are aware of a total of 122 cases of acute pulmonary hemorrhage in infants nationwide over the past 5 years. As you can see from the map that we handed out to you,

most of your States have had at least one case. Especially in the Chicago area, and also more recently in Milwaukee.

The rapidly growing lungs of young infants appear to be especially vulnerable to the toxins made by this mold. The CDC investigation also found that environmental tobacco smoke was frequently a trigger to precipitate the acute bleeding.

This is an emerging disease. We need to act now to learn how to prevent it and how to treat it. I urge you to provide new supplemental funds to both the CDC and NIH to address this problem.

The CDC needs, in our view, an additional $3 million in order to address several areas. They need to help us in northeastern Ohio, to the Ohio health agencies, who have already started a prevention program. We need to further investigate the Cleveland area to find out why we are having over a third of the cases in our immediate area, and also the other Great Lakes cities where they seem to be clustering.

We need to mount a nationwide study to see if the other infants that are having pulmonary hemorrhage also have toxic mold in their homes. The CDC needs to develop rapid methods to detect and quantify airborne toxic fungi in order for us to better make objective public health decisions, particularly whether it is safe for infants to remain in water damaged homes.

We urge you to provide to the NIH, specifically to the National Institute of Environmental Health Sciences, an additional $2 million to initiate research on tests to detect direct exposure, recent exposure to the toxic fungi, in order to help us diagnose this disorder more quickly. We need to develop infant animal models as a way to model how these toxins cause the human disease.

We need to find out why these infants continue to have low grade bleeding in their lungs, even though they have been removed from the toxic environment, both the fungus and the smoke environment. We need to determine the relationship of this disorder to the fatal mechanisms that occur in SIDS.

We urge you to help us attack this newly recognized environmental hazard that is killing young infants in our community. These fiscal requests are a crucial initial empowerment.

Thank you.

[The prepared statement of Dorr G. Dearborn, M.D., follows:]

[Pages 1179 - 1181--The official Committee record contains additional material here.]

Mr. Porter. Dr. Dearborn, thank you very much.

I personally was not aware, before your testimony, of this very serious problem. We will do our best to give CDC the resources they need to address it. Thank you for bringing it to our attention.

Mr. Stokes.

Mr. Stokes. In light of the fact that this new, emerging disease has attracted national attention in the media, I wonder

if I could just ask a couple of questions of Dr. Dearborn while he's here. Thank you.

Dr. Dearborn, I'm struck by the fact that you've made reference to the fact that there are 122 of these cases nationwide, and yet a third of the cases are in the Cleveland area, specifically in my Congressional district. Then about half of them are around the Great Lakes.

Do we know why we have that type of a phenomena?

Dr. Dearborn. No, we have a few speculations, but that's all they are at this point. They need to be investigated, particularly by the CDC, to see if we can find out why there is that clustering. It may have something to do with the older housing, but Cleveland is not the only city with older housing. It may have to do with the sewer system, but again, the sewer system is not necessarily unique to Cleveland. There are several clues we need to follow up.

Mr. Stokes. Is there any relation between this type of disorder and sudden infant death syndrome?

Dr. Dearborn. There appears to be some overlap, at least in the cases in the area of your district where we had a number of the deaths. Twelve percent of the deaths for a three year period, 12 percent of the SIDS deaths, were actually due to this disorder. This is not going to give us an explanation for the majority of SIDS cases, on the other hand, it will give us insight to a significant proportion of them, and in the process of researching this disease, we've already had some new insights, how to approach some of the questions that are being presented by SIDS.

So there is a small but meaningful overlap.

Mr. Stokes. My last question, Mr. Chairman.

Dr. Dearborn, as I understand it, of the 38 cases in the Cleveland area, 30 of them were African-American children, is that correct?

Dr. Dearborn. That is correct.

Mr. Stokes. And is the same true for the balance of the 122 cases? Would the majority of those also be African-American children?

Dr. Dearborn. The majority are African-American, probably about two-thirds. Another fifth are Hispanic and the remainder are of other Caucasian races. It appears to be more directly related to socioeconomic conditions than anything directly to race, although obviously we need more research to understand that.

Mr. Stokes. I appreciate the Chairman's reference to the fact that our committee will see that NIH gets the kind of money necessary to investigate this new and very serious emerging disease.

Thank you very much for your testimony.

Dr. Dearborn. Thank you.

Mr. Porter. Thank you, Mr. Stokes. Thank you, Dr. Dearborn.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness.]

Tuesday, February 3, 1998.

WITNESS

LOU HOLTZ, JUVENILE DIABETES FOUNDATION INTERNATIONAL

Mr. Porter. Next witness is Lou Holtz, Juvenile Diabetes Foundation International volunteer and former head football coach at Notre Dame University. Coach, it's good to see you.

Mr. Holtz. Thank you.

Mr. Porter. Mr. Dickey.

Mr. Dickey. I wanted to introduce you all to this man. Two steps before he was appointed by the Pope to coach Notre Dame, he coached at Arkansas. [Laughter.]

Mr. Porter. We won't hold that against him.

Mr. Dickey. I want to tell you--as you were. At Arkansas, I want to say this in all sincerity, he established what's called the do-right rule. He kicked some people off the team and they rushed up to him and said, why, and he said, because they didn't do right.

He has taken the loyalty of the State of Arkansas completely, 100 percent. This is a quality man. Whatever he puts his name behind, he has thought it out and it's worthy of listening to.

So I recommend Lou Holtz to you all and you to Lou Holtz, and this issue to us as a Nation. Thank you for coming, Coach Holtz.

Mr. Porter. Ms. Northup.

Ms. Northup. Mr. Chairman, I would also like to recommend Coach Holtz. Coach, both my parents went to Notre Dame and St. Mary's. I met my husband the first night of my freshman year at Notre Dame. And nine more of my sisters graduated from there.

So I think the gold on the dome might be out of the tuition that we spent over the years. But anyway, I can tell you that every game that Notre Dame plays is replayed in my house for a solid week until you know every play by heart.

We had great admiration for you, not only for your football, but also for the motivational talks that you gave in Louisville and other cities around the country, particularly the young people, about working hard and taking a chance. Those were very stirring words and stirred children and adults alike. I'm very happy to see you here, and my parents and husband will be thrilled to hear that I saw you in person.

Mr. Porter. Coach, even despite Mr. Dickey's endorsement, we are happy to hear from you. [Laughter.]

Mr. Holtz. Thank you, Mr. Chairman, distinguished guests and panel. It is a pleasure and an honor to address this group. I am not going to speak from any prepared notes, but I'm going to speak from my heart.

I'm hear to speak on behalf of 16 million people that suffer from diabetes. Eight hundred thousand people are going to be afflicted with it this year. Approximately on the average, 35,000 of your constituents have diabetes. That speaks to hundreds of thousands of people that become associated with it through that.

We need help. I'm here to say, we need help. We can't do it. We've tried. I personally have a son, Kevin, at age 15 was diagnosed with diabetes. We didn't even know what diabetes was. It was a shock to us. We found out that he'd have to take

insulin shots three times a day, he'd have to watch his diet.

What we really weren't prepared for was the psychological damage that it did to a 15 year old, to his self-confidence, to his decision making process. Thank goodness, my wife had the time, the effort and the resources to get him through that. He eventually went to Notre Dame and became a lawyer. He moved to Texas, passed the Texas bar, I told my wife it might be the first bar he'd passed since he turned 18, but we're very proud of him. [Laughter.]

It's been a very difficult struggle, but we feel we've been blessed. It's the leading cost. When you sit down and you find out all of a sudden, he has a better chance to have blindness, to have problems with his kidneys, his chances are greatly enhanced by two to four times that he's going to have heart problems, and the list goes on and on.

It really is something that we really are unaware of, because people try to hide it. They don't want to stand there and have people watch you take a shot or talk about diabetes. You can't tell who's a diabetic, but I can tell you this, it affects the family, it affects your health.

At Notre Dame, I find out my secretary's daughter was a diabetic and had all kinds of problems. I find out my assistant backfield coach was a diabetic. Our equipment trainer's wife was diabetic and blind at age 35. We played Michigan in 1980, and Friday morning I get a call, and thank goodness, my son lived with Kevin. He said, Kevin's in a coma. We rushed him to the hospital, he stayed in that coma from insulin.

What happened is, he went to be, and you have to take your blood and sugar and you get a reading, it's 125. You go to bed and all of a sudden it drops down, you go into insulin shock and you don't wake up any more. We didn't know whether he was going to make it or not.

Our story is not unusual. This is happening all the way around. We spend $137 billion a year on related illnesses or the caring for diabetes. We haven't cured it. All you're doing is going on a life sustaining project to be able to take insulin. There is no way in this world the free enterprise system is going to solve it, because they make a profit from diabetes.

Now, I'm not saying that they're for diabetes, but there's no great motivation. The only way this thing is going to be solved is through research.

I heard Peter Uberroth say at my son's graduation at Notre Dame, he said, if enough people care, you can solve anything. There are a lot of people who care about diabetes. I believe we raised $57 million last year in individual funds alone. That is an awful lot of money. You could purchase just about anything.

But we can't do it without help. We need the Government's help. And it's not just on my son Kevin. We're talking about 16 million people. I haven't even mentioned the families. We're talking about what happens years down the road.

I conclude with this. I've always told our football team to win. And win stands for what's important now. As I look at it, the future of the young people, I look at my grandchildren, I wonder if they're going to have it, I know the trials and tribulations, the pain and sorrow that goes along with it. So I'm here on behalf of 16 million people, saying we need help.

Thank you for your time and listening to me.
[The prepared testimony of Lou Holtz follows:]

[Pages 1186 - 1188--The official Committee record contains additional material here.]

Mr. Porter. Coach, let me say that, and I often say this, none of us up front here legislative in a vacuum. All of us have individuals in our families that have been touched by various diseases. My wife has diabetes, it came on two years ago, adult onset. I am very seriously concerned about her health, I can see the effects on her. What you tell us is all unfortunately too true.

That's the reason why this subcommittee has placed biomedical research at a very high priority. We've done our very best to provide the resources to science that it needs to unlock the key to this and other diseases. I can tell you right now we'll do our very best to continue to do that, place it at a high priority and give our research scientists the tools they need to get us by this.

Mr. Holtz. Thank you very much. Because I said to my son Kevin, you know, it wasn't a decision he made, it wasn't a choice. It's just congenital, and it's difficult to handle. But we appreciate it.

Mr. Porter. Thank you very much for coming here and testifying. You're making a difference, and that's what counts.

Mr. Holtz. Thank you very much.

Tuesday, February 3, 1998.

WITNESS

CLYDE McCOY, UNIVERSITY OF MIAMI

Mr. Porter. Dr. Clyde McCoy, Professor of Epidemiology and Public Health and Director, NIDA Comprehensive Drug Research Center, testifying in behalf of the University of Miami.

Dr. McCoy.

Dr. McCoy. Thank you, Mr. Chairman, subcommittee.

Boy, it's really tough following Notre Dame. [Laughter.]

Because I not only represent the University of Miami, but also Florida State University today. But before you leave, I do want to exclaim that I am Irish. I am also a direct descendant of the infamous McCoy clan from Eastern Kentucky, and a former professor at the University of Kentucky. Laughter.]

Mr. Chairman, members of the subcommittee, I do appreciate the opportunity to present testimony on behalf of the University of Miami and Florida State University, who is our in-state research and education partner, university-wide. This is a very unique partnership between two of our more prominent universities.

As yet, we haven't joined our football teams, Lou, but we're thinking about it.

We're deeply appreciative of your leadership, Mr. Chairman, and of the subcommittee's confidence. We're especially thankful

for the supportive language from your subcommittee over the past two years, and look forward to your continued support for this very unique collaboration in 1998.

I fully understand and appreciate that at no time in the past have you and your Congressional colleagues faced more challenges and more constraints. Thus, we appreciate even more your willingness to consider this important and unique university-wide research and education partnership.

Also as a former manager for Tom Luken, Mr. Stokes, who served on this Hill for more than 18 years, I am personally impressed with the dedication, commitment and hard work that all of you put in to serving this great country of ours. We feel strongly that the unique challenges that you face have never been greater.

At the same time, there has never been a time in history when there has been greater opportunity for the world to share in the accumulation of knowledge that could have healing and unifying consequences for all human populations. I think you're hearing from all those people here today.

People around the world thirst and hunger for our democratic way of life, which in large part is based upon the scientific enterprise, which allows us to be a knowledge based and democratic society which prizes knowledge and objectivity for supporting not only our health and our economy but also our political processes. We as scientists are most appreciative to you for funding the most science based society ever.

The University of Miami and Florida State University Risk Assessment and Intervention Consortium is dedicated to reducing medical and social costs through the development of cost efficient, effective delivery of earlier interventions. Our consortium will bring together scientists from a very broad array of traditional research disciplines to face scientific challenges in a trans-disciplinary and timely manner.

In the last 50 years, as you know, tremendous strides have been made by the sciences to improve our world's health and environment. It now appears that the next major breakthroughs for improving quality of life and for reducing socioeconomic costs lie at the intersections of those sciences.

Presently, these various sciences and institutes that fund them work too independently from one another to optimally address the broad and interrelated nature of these problems. To fully consider specific policy implications, or to allow for the investigation of the most threatening risks in the most timely manner.

My own scientific research is somewhat unusual, in that I have conducted research and published in three broad disciplinary areas of cancer, HIV and substance abuse in many countries, with many hundreds of scientists. This perspective of more than 25 years makes me yearn for a greater scientific enterprise that allows us to reach across these various disciplines in order to investigate problems more quickly and to apply the findings in a much more rapid manner.

We feel that our consortium will provide this type of partnership between science and government to assure a more optimal and cost effective quality of life. Risk assessment as a field incorporates scientists from a wide range of disciplines and directs their attention specifically to

controlling, regulating or intervening with populations at risk as early as possible.

At present, there is no identifiable broad based institution we know of that concentrates solely upon the full and complex range of risks utilizing multi-disciplinary and trans-disciplinary science. Therefore, our consortium will be in a perfect position to improve quality of life, decrease mortality and morbidity, and through identifying risks earlier and by intervening earlier, be in a position to save millions, if not billions, of dollars through the application of knowledge to early intervention.

We know that intervention with effective prenatal programs saves a tremendous amount of money that otherwise would be spent on children after birth. Also, our own research experiences with the early detection of breast cancer have demonstrated through the screening of over 30,000 medically underserved women, using an efficient mobile van, rotating among 12 primary public health centers, that these programs not only save lives, but save dollars.

As is true for cancer, we already possess a great deal of knowledge that could be used to develop interventions as well as preventive strategies for many other diseases that present challenges throughout the world, such as HIV, substance abuse and others that you've heard about here today. With the increasing costs of institutionalization and public subsidies and of Medicaid and Medicare, every person who we prevent from being institutionalized or dependent on public subsidies not only saves governmental dollars, but will also add to the economy of this country.

Just as important, the quality of life for these individuals, their families, their communities and our society at large, will be improved. It is becoming ever more apparent that we as a Nation cannot afford to ignore prevention in early intervention strategies, since later management and later treatment are much too costly in the terms of quality of life and necessary expenditures of dollars.

Our proposed organization will cross disciplinaryboundaries to accomplish these goals for us.

We thank you so much for your valuable time and stand ready to serve you in any way possible.

[The prepared statement of Clyde B. McCoy follows:]

[Pages 1192 - 1201--The official Committee record contains additional material here.]

Mr. Porter. Dr. McCoy, thank you very much for your strong and good testimony. Again, we will do our best.

Dr. McCoy. Thank you very much.

Mr. Porter. Thank you, sir.

Tuesday, February 3, 1998.

WITNESS

ROBERT M. CAREY, M.D., ASSOCIATION OF AMERICAN UNIVERSITIES

Mr. Porter. Robert M. Carey, M.D., Dean of the University of Virginia School of Medicine, testifying in behalf of the Association of American Universities. Am I correct, Dr. Carey, that you are accompanied by Sue Quantius?

Dr. Carey. Yes.

Mr. Porter. One of the most able people ever to serve on Capitol Hill, and as a member of the staff of this subcommittee, Sue, it's really wonderful to see you. Thank you for being with us.

Dr. Carey, we welcome you.

Dr. Carey. Thank you, Mr. Chairman.

Mr. Chairman, distinguished members of the subcommittee, I am Dr. Robert M. Carey, Dean of the University of Virginia School of Medicine. I am pleased to be here today representing the Association of American Universities, the AAU, an organization of 62 public and private research universities across the United States and Canada.

Today, we are pleased to have the opportunity to speak about a Federal program of enormous importance to our universities, research supported by the National Institutes of Health. We come before the subcommittee at a time of great promise for biomedical research. We are grateful for the subcommittee's consistent, strong support of the NIH. You have been champions of biomedical research, particularly you, Mr. Chairman, even when substantial cuts were being made elsewhere in your appropriations bill.

Your commitment to biomedical science has cone much to create the current atmosphere in which support for the NIH is spreading throughout the country. We are greatly heartened by the groundswell of public sentiment for investing in biomedical research, and the possibility that the healthy economy and the fiscal accomplishments of Congress will permit financing this priority.

You have already heard many witnesses describe the tremendous opportunities in science and the breathtaking speed at which discoveries are being identified. I would like to give you one example that comes from my own field, high blood pressure research. High blood pressure, or hypertension, is the most common cause of heart failure, which in turn is the most common reason for hospitalization over the age of 65.

Hypertension is caused by the interaction of many different genes. In the past, the polygenic inheritance of blood pressure has prevented our understanding of the mechanisms underlying hypertension. Therefore, we do not have a treatment of hypertension specific for the cause of that disease.

Recently, the gene for a hormone, angiotensin, has been shown to account for a substantial fraction, about 15 percent, of hypertension for the first time. Clearly, the techniques of molecular biology are poised to open the door to specific treatment and cure of high blood pressure, once its genetic determinants are known.

The AAU supports efforts underway throughout the biomedical community to increase substantially funding for the NIH. We join the ad hoc group for medical research funding in its call for a 15 percent increase for NIH in fiscal year 1999 as the first step in a five year effort to double the NIH budget.

We are greatly encouraged by the President's request for an 8.4 percent increase for the NIH as the starting point for the debate this year. The AAU would like to highlight needs which should be addressed if new resources become available. The AAU continues to emphasize the investigator-initiated grant as the bedrock of the NIH.

We also want to focus attention on pressing needs in two areas, clinical research and institutional infrastructure. The dominance of market forces in the health care system has drained resources that previously had been used to support clinical investigation and clinical investigators. Training and career support for clinical researchers at all levels needs strengthening.

The general clinical research centers program, which supports inpatient and outpatient research facilities, training research support staff and other resources crucial to clinical investigation, should be targeted for additional resources. The second area of concern is institutional infrastructure. Additional resources need to be invested in renovating outdated facilities, supporting animal research facilities, financing instrumentation, and developing new research technologies.

In addition, the AAU encourages Congress to consider reinstituting a peer reviewed accountable institutional grant program that can be targeted to specific institutional needs. Mr. Chairman, thank you for this opportunity to express our views and add our voices to the growing chorus of advocates for biomedical research.

[The prepared statement of Robert M. Carey, M.D., follows:)

[Pages 1204 - 1209--The official Committee record contains additional material here.]

Mr. Porter. Dr. Carey, thank you very much for your excellent testimony. I have to say, it just happens that you're the one to receive my sermonette, because I've given it to every panel that has come before us in this session. And it goes something like this.

This subcommittee, I think, would place raising the support for biomedical research at a very high priority, and would commit the resources to doubling the research enterprise over the next five years, if we have the resources with which to do it. The difficulty is that even the President's budget, and he's suggesting only doubling the commitment over 10 years or 50 percent over 5 years, even the President's budget depends upon revenues that we think are not likely to materialize in the budget process here in the Congress.

He's got about $100 billion of net new revenues, a large part of which is a tobacco settlement that I don't think is going to happen, and other increases in taxes that i don't think are going to be voted. That means it's going to be difficult for this subcommittee to get the kinds of resources that we need in our budget allocation without some real strength in the Budget Committee.

We hear you very clearly, very loudly. We need your help in the budget process as well, however, to give us the tools we

need to work with, so we can give you the tools you needto work with. That's my sermonette, and I thank you very much for listening to it and for testifying.

Dr. Carey. I thank you so much for your support.

Mr. Porter. Thank you, Dr. Carey.

Tuesday, February 3, 1998.

WITNESS

ANTONIO DE LA CRUZ, M.D., AMERICAN ACADEMY OF OTOLARYNGOLOGY-HEAD AND NECK SURGERY, INC.

Mr. Porter. Antonio De la Cruz, M.D., President, American Academy of Otolaryngology-Head and Neck Surgery, Inc., testifying in behalf of the American Academy of Otolaryngology and the Head and Neck Surgery Inc.

Dr. Rubin. Good afternoon. I'm Dr. Rubin, and I'm here to introduce our President, Dr. Antonio De la Cruz, who will testify. However, before we begin, I'd like to tell you how much we appreciate your work, Mr. Chairman, and that of the subcommittee for the past several years. For without your leadership, the marvelous groundswell of support for the NIH that we see would not have occurred.

Dr. De la Cruz. Mr. Chairman, thank you for the opportunity to present my testimony, and for all that you have done in the past.

Thanks to leadership like yours, and the funding of NIH, we have a real chance to wipe out communication disorders, or at least to improve them significantly. In the last few years, we have been able to detect some of the genes of hereditary deafness. We have been able to improve in the reconstruction of holes in eardrums and replace little bones to improve hearing of something that has occurred. We have developed an electronic ear that can replace nerve loss. For the first time we are able to stimulate the brain that way and replace an organ.

But we are at the brink. We have a good chance to eradicate, or to have a significant impact on communication in the next few decades. We are indeed needing the basic research that only government can do to establish more of the genetic basis of disease.

We also became aware, yesterday we spent all day at NIH, and particularly at NIDCD, the deafness and communication disorders, the smallest and the youngest of the Institutes of Health. Analyzing the economic consequences of communication deficits and the social price of that, it became obvious after seven or eight hours of analyzing the situation how our ability to earn a living has changed.

From the beginning of the century, where manual labor was the most important element, to today's communication. We feel that in this year, the projections of the Bureau of Labor is that by the year 2005, 92 percent of all jobs will require a tremendous amount of communication.

So we think we have a tremendous impact. The National Institute of Deafness and Communication Disorders has a mission to put together the social impact and the basic research, the technology to try to make those individuals productive in our

society. Not only the tremendous price of human pain of being deaf or not being able to speak or have a language disorder or speech disorder, but also the cost to our country.

The productivity of the individual today, with computers, with telephones, with faxes, is depending on communication. So we are part of the ad hoc group of labor, and I mentioned to you, we are looking for a 15 percent increase. Actually, asking for NIDCD, the Deafness and Communications Disorders, an 18 percent. Because we feel that the urgency of the smallest and the youngest of the Institutes is there.

We did work this morning with the Budget Committee trying to find other avenues to afford to you the caps and the amounts, to see if we can make a tremendous difference in the next few years.

I want to thank you personally on behalf of the Academy, which represents 10,000 otolaryngologists and the largest organization in the world, for all that you have done in allowing us to get where we are today.

[The prepared statement of Antonio De la Cruz, M.D., follows:]

[Pages 1212 - 1220--The official Committee record contains additional material here.]

Mr. Porter. Thank you very much for your testimony, Dr. De la Cruz. I think NIDCD is no longer the youngest. In fact, I think there are two younger institutes.

Mr. De la Cruz. It is very young and one of the lowest. When you see all the budgets----

Mr. Porter. Human genome research and nursing are both younger, if I'm correct.

Mr. De la Cruz. They are the youngest, and when you see all the fundings of the National Institutes of Health, it's way down on the right hand. We want to move it to the middle somehow.

Mr. Porter. That message I got very clearly. [Laughter.]

Mr. Porter. We thank you for your testimony, and we'll do our best, as you know, to put it at a high priority.

Dr. De la Cruz. Thank you very much, Mr. Chairman.

Mr. Porter. Thank you.

[Clerk's Note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives wa snot received from this witness or from an entity represented by the witness]

Tuesday, February 3, 1998.

WITNESS

DEBBIE FLADER, ADVOCATES FOR EPILEPSY

Mr. Porter. Our next witness is Debbie Flader, parent of a child with epilepsy and National Co-Chair of Advocates for Epilepsy, testifying in behalf of the Advocates.

Ms. Flader.

Ms. Flader. Good afternoon.

I am the parent of a child with epilepsy. I'm here today on her behalf and on behalf of hundreds of thousands of other children and families with epilepsy across America. Thank you, Mr. Chairman, and members of this committee, for inviting me to share my story with you today.

Six years ago a nightmare began for my family that has profoundly changed our lives. On February 12, 1992, my daughter Noel began to display neurological symptoms that we neither recognized nor understood. Noel was eight years old, and she had been a perfectly healthy child, but on that day, she began to complain of bizarre sensations, a feeling that she had a bubble in her cheek, and that her hands were falling, a complaint that her teeth hurt.

With days, these symptoms worsened, and we realized that something very dreadful was happening. The day my daughter developed epilepsy, we joined two and one half million other American families who also are affected by this disorder.

Approximately 30 percent of people with epilepsy do not respond to current therapies. Nearly one million people with uncontrolled intractable seizures. And 30 million Americansdie each year of epilepsy related causes. Noel is one of those 30 percent whose seizures cannot be controlled.

A week after the initial symptoms surfaced, we noticed further signs of trouble. Noel's eyes and mouth began to twitch periodically and she began to drool. Our family physician scheduled an MRI to search for more reasons for these spells, as we called them. Though these twitching and drooling episodes were coming by the hour, the MRI showed nothing.

We went home and watched helplessly as Noel's condition deteriorated. The pain in her teeth became excruciating. The spells were now occurring every 15 minutes. She lay awake most of the night with the right side of her face twitching.

We took her to a neurologist, but after an exam and an EEG he called normal, he sent us home with Advil for pain in her teeth and a diagnosis of a psychosomatic illness. This doctor then explained that Noel was probably exhibiting a typical middle child reaction to not getting enough attention at home. We knew, however, that her suffering was very real.

Finally, we took Noel to Children's Memorial Hospital in Chicago. After weeks of tests, we were told that she had epilepsy.

Noel remained alert during her seizures, which by now would last up to an hour. Imagine watching your child's face contort and twitch for that long a period. Imagine that she be conscious, yet unable to control her body's movement. Imagine the sense of helplessness you feel.

Noel was given many different anticonvulsant medications, but to no avail. She vomited constantly, but the seizures still continued, one after another. She was started on a very, very high dose of Prednisone, a corticosteroid, and this seemed to calm down the seizures a bit.

We witnessed a total personality change due to the medication. Our once playful and happy child was angry with everyone and everything. She used foul language and became very violent. We desperately searched for a better answer.

In August of 1992, Noel had an EEG and an MRI, and this

time a small lesion was found on her brain. To rule out an underlying tumor, a biopsy was done, along with a sub-peel transection, which is a surgery designed to break up the electrical current in the brain without removing any tissue, a technique that sometimes is effective in limiting seizures, though not for Noel.

Fortunately, there was no tumor. The post-surgical diagnosis was Rasmussen's encephalitis, a sometimes degenerative condition of the brain that can cause epilepsy.

What's disturbing is that the nature of Noel's seizures has changed. She now has what are called atonic or drop attacks. This means she can fall at any moment and severely injure herself. She can no longer attend school with other kids. She is presently tutored at home to avoid the risk of injury. For a young teenager, this is no life.

Recently, along with other parents, I have formed Advocates for Epilepsy. Our hope is that by telling our stories, which mirror the experience of hundreds of thousands of other children and families across this country, we can persuade you to devote more resources to the fight against epilepsy.

We are grateful to the Epilepsy Foundation of America and the Epilepsy Foundation of Greater Chicago for supporting our efforts. Perhaps because many people assume epilepsy is easily treated by medications, or perhaps because it is a disorder that for thousands of years has been stigmatized by those who don't understand it, the investment in epilepsy research has lagged far behind what is needed.

Though millions of Americans like Noel struggle with epilepsy, Federal research dollars into this complex short circuiting of the brain currently amounts to just $20 per patient per year. As the accompanying chart reflects, that is comparatively little. We are asking that you triple research dollars spent on epilepsy. Specifically, we're requesting an increase from the current $54 million to $130 million in the next fiscal year.

These are dollars we desperately need to unlock the mysteries of the brain. We need new research, new solutions, and much more energy in the field.

The future of our children depends on this effort. The future of all people with epilepsy lies in discovering causes, new treatments, and potential cures. Although 75 percent of epilepsy begins in childhood, anyone can develop epilepsy at any time in their lives.

With the current low level of funding, new discoveries to help these people are a long way off. We appeal to your sense of compassion, but we also want you to know that beyond the personal costs, the costs to our Nation of intractable epilepsy are staggering. Frequent emergency room visits, lost school days, special ed, inability to work, dependency on families and permanent government support, these costs, which amount to some $3 billion per year, far outweigh the investment in medical research we are requesting.

In closing, Mr. Chairman, let me say that our children's lives are passing quickly, brutalized by repeated seizures and living under the veil of heavy medication. They truly are our heroes. It is now time for us to become their heroes.

Please help us to succeed in finding better treatments and

possibly even a cure for epilepsy.

[The prepared statement of Debbie Flader follows:]

[Pages 1224 - 1228--The official Committee record contains additional material here.]

Mr. Porter. Ms. Flader, thank you for your testimony.

You're a Chicagoan, right?

Ms. Flader. Yes.

Mr. Porter. You mentioned the Children's Memorial, which is one of our great treasures in the City of Chicago, and apparently had some degree of help for your daughter's disease.

Ms. Flader. Some. I've traveled all over the country looking for better. One seizure per day is not satisfactory. I need no seizures.

Mr. Porter. But they were the first, according to what I thought you said, to actually identify this.

Ms. Flader. Right. They did help me, right.

Mr. Porter. One thing I want you to know, and I think it's very important that people understand this, and that is that we do not fund by disease. We fund by Institute.

Ms. Flader. I understand that.

Mr. Porter. I knew you understood it, but this is sermonette number two. We do, however, and very forcefully, I think, attempt to influence the direction that NIH takes in respect to its priorities. I think NIH has been very responsive to the concerns that Congress expresses. Yet we are very careful not to override scientific judgment with political judgment.

I think that's exactly the way this ought to work. And it is a cooperative endeavor, in a very real sense, that we engage in with NIH to attempt to work with them on priorities. And yet, in the final analysis, NIH makes those decisions through science and not through the political process.

We appreciate your testimony. There's been a number of groups here to testify on epilepsy. Is there some coordination between them?

Ms. Flader. Yes, we're being supported by the Epilepsy Foundation of America, and the Epilepsy Foundation of Greater Chicago. We've been working together collaboratively on this issue, trying to get more Federal dollars for research.

Mr. Porter. We're going to do our best.

Ms. Flader. Thank you.

Mr. Porter. Thank you for testifying.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness]

Tuesday, February 3, 1998.

WITNESS

A. GERALD ERICKSON, METROPOLITAN FAMILY SERVICES

Mr. Porter. A. Gerald Erickson, President, Metropolitan Family Services, testifying in behalf of Metropolitan Family Services. Gerry, it's very good to see you. We thank you for coming to testify. Another one of the treasures of our city.

Mr. Erickson. Thank you for having me. If I might do a quick sort of reverse sermonette, I just wanted to say a word in support of Coach Holtz' testimony, my wife and I are also parents of a juvenile diabetic. And everything he said was certainly right on.

I'm also aware of the leadership that you've given in this area in the past, and just wanted to say a word of appreciation.

Thanks for the opportunity to testify again this year. I am testifying on behalf of Metropolitan Family Services of Chicago. We are a comprehensive, non-profit, non-sectarian human service organization that serves over 100,000 families a year in the Chicago area.

While our focus on working with families has remained constant, the needs of families have changed as culture and policies have shifted. As communities, public systems and families express needs, we respond. I present this testimony this year to provide a status report on Metropolitan Family Services' ongoing efforts to be innovative and effective in our programming in the areas of community violence prevention, mental health services and elder care.

Since the passage of the Violence Against Women Act in 1994, community coalitions to prevent intimate partner violence have been forming all over the country. In the context of this movement, we have been discussing an exciting new initiative with the Centers for Disease Control and Prevention which we are calling Coordinated Community Responses to Prevent Violence.

CCR will provide resources for communities to develop, implement and evaluate violence prevent programs in the following areas: intimate partner violence, youth violence, sexual assaults, suicide, child abuse, elder abuse and gang violence. The basic concept behind CCR is to engage the community itself in defining the problems and molding the solutions that are most likely to create genuine systemic change.

At Metropolitan Family Services, we have experience in collaboration with local residents, service providers and business, religious and civic leaders. Our community development methods enable whole communities to respond to and solve complex social problems. Mr. Chairman, we ask that the subcommittee encourage the CDC to continue to explore CCR as a program concept.

We also provide needy Chicago area adults, children and families with a comprehensive range of community based mental health services. We know from experience with emotionally disturbed children that early intervention, treatment, parent education and other supports to families make a difference in ameliorating more serious conditions in the future.

With an early intervention approach in mind, Metropolitan Family Services has developed a model for identifying young children and families at risk for behavioral disturbance,

mental illness, and substance abuse. The cutting edge model would bring behavioral health care services and other needed resources directly to families within an early childhood setting. The model seeks to support and empower parents to become the primary intervention agents for their own children.

We ask that the subcommittee urge the Department of Education to consider demonstrating and evaluating such an early intervention model so that emotional and/or behavioral problems can be identified and dealt with early on.

Finally, Mr. Chairman, we would like to bring the subcommittee's attention to a study by the National Alliance for Caregiving, which revealed that nearly one in every four households is involved in family caregiving to elderly relatives or friends. The present division of acute and long term care for the elderly is ineffective and costly, especially in responding to the needs of the elderly with chronic conditions.

The current system also penalizes family involvement in the care of the elderly. We believe that a conscious effort should be directed toward the development of innovative family and community responses to the care of the elderly. We ask that the subcommittee encourage HCFA to work with community based organizations to create long term care systems that recognize the role of the family in caring for elderly relatives.

Thank you for the opportunity to present this testimony again this year, and for the opportunity also to visit with you some months ago.

[The prepared statement of Gerald Erickson follows:]

[Pages 1232 - 1241--The official Committee record contains additional material here.]

Mr. Porter. I appreciated that opportunity, also. Mr. Erickson, you talked about the new violence prevention initiative that you're working on. How does that differ from what CDC has done in the past in this area?

Mr. Erickson. The difference is that CDC currently does its program by age grouping. I think their interest in us and our interest in them goes to the fact that we work with the full continuum, so that we would be not only dealing with teen violence, but at the same time, elder abuse. We would involve the community in developing the solutions. Again, a kind of a bottom up approach. The violence, in a continuum in the community, rather than to take out difference pieces as is currently done.

Mr. Porter. I'm very impressed with what Metropolitan Family Services is doing, not only in terms of making changes in peoples' lives who need the attention, need help, but also involving people throughout the Metropolitan area who care about one another in that process, and bringing a lot of private resources as well as public resources to bear on these problems.

So you're doing a wonderful job, and we appreciate your coming here to testify.

Mr. Erickson. Thank you very much.

Mr. Porter. Thank you, sir.

Tuesday, February 3, 1998.

WITNESS

MARY WOOLLEY, RESEARCH! AMERICA

Mr. Porter. Mary Woolley, President, Research! America, to testify in behalf of Research! America.

Mary, it's nice to see you.

Ms. Woolley. Thank you, Mr. Porter.

Chairman Porter, I'm Mary Woolley, President of Research! America, a national not for profit public education and advocacy alliance, dedicated to making medical and health research a much higher national priority. On behalf of our more than 350 members, individuals, academic institutions, corporations and voluntary health organizations, we thank you for your leadership when it comes to medical research. Medical research is a national issue, and it is also, as we have heard so persuasively this afternoon, a deeply personal issue that impacts every American.

Research! America is proud to serve as a voice for citizens who are concerned about medical research. Since 1992, we have commissioned regular national and state based public opinion polls, and have regularly conducted focus groups to explore attitudes and identify citizen issues and concerns regarding research. What we have found is that all over the country, citizens place their trust in research and research-based organizations to make the discoveries that will translate hope into cures, preventions and treatments.

We've also learned that citizens look to you and all our elected representatives to provide the resources to makethose discoveries possible.

Along with the American Medical Association, whose house of delegates recently passed a resolution in favor of doubling the National Institutes of Health budget, and the Ad Hoc Group for Medical Research, whose eloquent statement calling for a 15 percent increase this year in the NIH budget we heartily endorse, and the many other concerned organizations, Research! America is convinced that because we have invested and now have in place an army of gifted researchers, and because the opportunity in science is at an extraordinary level right now, now is indeed the time for a concerted effort to double the budget for the NIH over the next five years.

With your leadership, we think this goal is attainable. The public supports this goal, as you can see on our poster here. This data is from our most recent poll, in which 61 percent of American citizens say they favor doubling medical research. Now, this poll was taken just about a year ago. But I am gratified to be able to announce here that just last month, January 1998, a Wall Street Journal-NBC national public opinion poll found that by better than a two to one margin, a little better than we saw in our poll, the actual numbers are 64 percent favoring and 25 percent opposed, the public favors doubling the current NIH budget of $13 plus billion over a five

year period.

With the commitment of this subcommittee, accompanied if necessary by innovative additional funding mechanisms, doubling the NIH budget, we think, can become a reality. The public, in fact, is willing to contribute additional funds to make this possible. Research! America has tested several possible mechanisms for identifying additional monies to supplement appropriated dollars to accomplish the doubling goal.

Among those, timely, in light of possible tobacco settlement, is our finding that about 63 percent of the public say that they would sign a petition to increase cigarette taxes to provide funding for medical research. You see that here. We believe that a similarly high percentage, or even higher, would agree with dedicating a portion of new taxes enacted in conjunction with a tobacco settlement, cigarette taxes.

Now, so far, this is admittedly only an opinion, but later this month, our new polls will test citizens response to that very question. And I look forward to being able to advise you and all the members of the subcommittee of the results of those new polls.

Another mechanism also in the realm of the hypothetical, but greatly hoped for in many quarters, involves a budget surplus. Citizen priorities for surplus generated dollars has been tested by many polls of late. When Lou Harris and Associates asked citizens this past November how they felt about money from a budget surplus being used for additional spending on current programs, 81 percent said they would support surplus dollars going to medical research.

Now, based on our Research! America findings in polls and focus groups, there are just two other points I would like to emphasize concerning the decisions you and your colleagues will be making about research in this Congressional session. Both concern the fact that citizens do not want doubling of the budget of the National Institutes of Health to come at the expense of other health and science programs.

Research! America polls show that citizens value prevention research, for example. It is not surprising that there is such strong interest in prevention research, since everyone would agree that the ultimate goal is to eradicate, not just ameliorate, dreaded diseases like cancer, AIDS, diabetes, heart disease and stroke.

What is surprising is that funding support does not match the public's mandate. This public mandate translates to achieving stronger support for the Centers for Disease Control and Prevention and the Agency for Health Care Policy and Research in tandem, not instead of increasing support for the NIH.

My final point is based on a finding from our polls that strongly supports Federal investment in scientific research of all kinds as conducted in universities. New ideas and breakthrough technologies in fields such as engineering, physics, mathematics and chemistry have been instrumental to progress in the life sciences in the past. And this important synergy must be nurtured as we move into the new millennium.

Doubling the NIH budget in five years is the right first step to achieve the great promise of research. Doubling the NIH budget in five years would allow the 105th Congress to place

its stamp on history, contributing in never before possible ways to the health and quality of life of Americans.

In poll after poll, the message is clear that citizens back you and all our elected representatives when it comes to seizing the opportunity that science offers at this moment in our history. Nothing less than the health and well-being of my family and yours and that of every American is at stake. We put our trust in our elected representatives to make the investments it will take to hasten the day when we will speak of cancer, premature heart disease, AIDS, diabetes, and a host of other dreaded diseases, as finally conquered by American scientific know-how.

Thank you.

[The prepared statement of Mary Wolley follows:]

[Pages 1245 - 1258--The official Committee record contains additional material here.]

Mr. Porter. That's a wonderful statement.

Mary, what's the relationship between Research! America and the Ad Hoc Group for Biomedical Research?

Ms. Woolley. We work very closely together, Mr. Chairman. The Ad Hoc Group has many members, almost the same membership as Research! America. The Ad Hoc Group carefully, every year, evaluates with the help of many scientists the potential for what can be accomplished in science, and makes a recommendation as to what the budget should provide for the science.

What we do is test the citizenry's attitudes about using their public dollars in its support.

Mr. Porter. If I can express something and you can evaluate this for what it's worth, I'm kind of surprised at the degree of opposition in your survey of 1996, that was about a third of the people who answered yes or no answered no. And you say 25 percent now, what would be about a quarter in a more recent survey. I think I was even more surprised at the 34 percent who said they wouldn't use an increase in cigarette taxes or they wouldn't advocate for an increase in cigarette taxes to be used for biomedical research.

I think we've got to work on these people.

Ms. Woolley. You bet.

Mr. Porter. I don't understand, especially the one on smoking. The degree of cost to society of nicotine addiction is huge. If there was ever a justified source in my mind, and I may differ from others, but in my mind for funding biomedical research, it's a tax on tobacco and tobacco products.

So I'm surprised that the numbers are that high. I wonder if they, often our surveys stop before they get to the really significant questions. Okay, if you're opposed, why are you opposed? What is in your mind that leads you to that. Did you ask the further questions?

Ms. Woolley. What we do is in our focus groups we go to the next level.

Mr. Porter. You get that in focus groups.

Ms. Woolley. It's difficult to do that in polls, because then you get into a lot of open-ended sampling that's hard to

record and a lot of judgments have to be made about the recording.

But in focus groups, negatives come from a lot of different directions. They come from feelings against the government in general, anything having to do with the government then becomes a negative for some people.

But I think your point about the need to get to the people who are feeling negative is an important one. And through a program that we're operating called the 435 project, we're providing the tools and some assistance andmotivation to members of the scientific community to get out into their own local towns and surrounding areas and answer citizens' questions about research and make the case.

Mr. Porter. Absolutely. I know you're doing this, and I think that is absolutely the way to go about it, face to face communications, and where you can't have that, op ed pieces or letters to the editor, something to have the scientific community make the case for research I think is very, very important to establishing that as a priority among the American people. Because after all, what we do here is just listen and respond to what people think back home.

Ms. Woolley. Well, you can teach the rest of us a lot about communication, and we're trying to learn.

Mr. Porter. Well, you're doing an excellent job. We thank you for all that you do and for coming here to testify today.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness]

Tuesday, February 3, 1998.

WITNESS

JUDITH FLINK, THE COALITION OF HIGHER EDUCATION ASSISTANCE ORGANIZATIONS

Mr. Porter. Judith Flink, President, the Coalition of Higher Education Assistance Organizations, testifying in behalf of the Coalition.

Ms. Flink. I'm the Director of Student Financial Services at the University of Illinois at Chicago, President of the Coalition of Higher Education Assistance Organizations, the wife of a high school teacher at Waukegan High School, but most importantly, a parent. It is an honor to appear before you today to present testimony regarding the importance of continued Federal support for the Federal Perkins loan program.

As you know, the student body at UIC is rich with ethnic and cultural diversity. Of the 26,000 students at UIC, 74 percent receive some form of Federal financial assistance. We have participated in the Perkins loan program since its establishment in 1958.

Over 20,000 students have borrowed over $38 million. Nationally, $13 billion has been borrowed. Last year, our campus received $614,000 in funding from the Federal capital contribution, which we matched with $250,000, further expanding

available Perkins funding.

The Perkins program is a crucial resource for needy students. Mr. Chairman, in 1996, Perkins loans went to approximately 750,000 students at over 2,700 participating institutions. Furthermore, the 5 percent interest rates makes Perkins affordable for students with limited resources.

The $135 million Federal capital contribution that was appropriated by Congress in fiscal year 1998, combined with other funding, leveraged over $1 billion in new loans for undergraduate and graduate students throughout our Nation. Approximately 77 percent of Perkins borrowers are from families with incomes of less than $42,000 per year, and 25 percent of these borrowers are from families with incomes below $24,000.

Federal legislation places borrowing limits on guaranteed and direct loans, making the Perkins loan the vital gap filler for eligible low income students. Without Perkins, the alternative are limited to costly plus loans or private label loans, which are often unrealistic options for these students, because they require either creditworthiness or a co-signer.

Every year, financial aid administrators are forced to tell thousands of eligible students that they cannot obtain a Federal Perkins loan because of insufficient funds on our campuses. The average loan of $1,500 is well below the statutory limits. These students, some of the neediest in the country, are forced to turn to more expensive borrowing options.

For example, this year at UIC, we'll loan $3.9 million to over 1,800 students. However, we could loan to 3,600 students $7 million.

Let's turn now to the charts. The first chart depicts the cost of attendance at a State university. As is typical of many Perkins borrowers, the student has need, but does not receive a maximum Pell Grant. The State grant is significant, and the student will work for Federal work study funds. However, she'll still need to borrow.

The $2,625 represents the maximum amount of a subsidized Stafford Loan fund that is available to her. Her remaining unmet need of $3,000. In this situation, Mary could be awarded a $3,000 Perkins loan.

The second chart compares the total cost to borrowers of various federally supported loan programs. As you can see, a $15,000 loan costs the students much more than its face value. However, the Perkins loan is the best economic option for the students to meet the cost of their education.

In addition to the interest rate of 5 percent, Perkins loans offer students pursing degrees in teaching or other community service professions valued cancellation benefits. The Administration and other law makers including Representative Bill Paxton from New York have proposed new programs offering student loan forgiveness in exchange for teaching. The Perkins program is the logical program to serve as the basis for this initiative.

Additional funding for the Perkins program would serve students' needs and would prove more cost effective than the creation of a new program or new benefits in existing programs.

Most importantly, it would revitalize the original purpose behind the enactment of the Perkins loan program, providing low

cost loans and a cash cancellation incentive to the future teachers of America.

Since 1980, the purchasing power of the Perkins loan has eroded 90 percent relative to inflation. The Administration's fiscal year 1999 request of $60 million in new FCC funds, combined with $40 million from recaptured dollars in the program, will further this decline. COHEAO would like to request an increase in funding for the Perkins program to $200 million in FCC. This increase will allow more schools to lend more money to more students and to begin to alter this negative trend.

I appreciate having the opportunity to testify before you today on the importance of the Federal Perkins loan program. On behalf of UIC and COHEAO, and most importantly as a parent, I urge you to consider the legislative proposal I've discussed regarding this very important program. Keeping the Federal Perkins loan program strong is one way we can promote access to higher education.

[The prepared statement of Judith Flink follows:]

[Pages 1262 - 1271--The official Committee record contains additional material here.]

Mr. Porter. Are the interest figures you show up there today's figures?

Ms. Flink. Yes. For instance, the spread between a Perkins loan and a Perkins loan, the Perkins is 5 and your subsidized loans are 8.25. Then it goes up from there.

Mr. Porter. And the pluses, it represents sort of a market value today?

Ms. Flink. To parents, yes.

Mr. Porter. Right.

Ms. Flink. It's the parent loan to undergraduates.

Mr. Porter. There's a big difference between the plus loan, for example, and the Perkins, a huge difference.

Ms. Flink. Yes. The Perkins loan is what we would really like to be giving to our neediest students, versus the more expensive options.

Mr. Porter. Well, we thank you very much for testifying. Your husband teaches at Waukegan High School?

Ms. Flink. Yes, he started two years ago.

Mr. Porter. And where do you live?

Ms. Flink. In Morton Grove, grew up in Northbrook.

Mr. Porter. Oh, you're almost in my district. [Laughter.]

I used to represent Morton Grove, but they took it away from me in 1982.

Ms. Flink. But I was born in your district, and he teaches in your district.

Mr. Porter. So in the morning you get up and go in opposite directions. You go south and he goes north.

Ms. Flink. That's kind of why we ended up right where we are, 35 minutes either way.

Mr. Porter. Oh, Morton Grove's a really nice community, and I'm sorry I don't have it any more. Well, we very much appreciate your testifying.

Ms. Flink. Thank you very much.

Tuesday, February 3, 1998.

WITNESS

JOYCE WESSEL RAEZER, NATIONAL MILITARY FAMILY ASSOCIATION

Mr. Porter. Carl M. Kuttler, Jr., President, St. Petersburg Junior College, St. Petersburg, Florida, testifying in behalf of the college. Is Mr. Kuttler here? He apparently is not. If he arrives later, we will put him back in the rotation.

Joyce Wessel Raezer, Educational Specialist for the Government Relations Department, testifying in behalf of the National Military Family Association.

Ms. Raezer. Thank you for allowing us to be here today to speak on behalf of military families and military children.

Mr. Chairman, NMFA and the families we represent are grateful to you and the subcommittee for your untiring efforts on behalf of military children and the Impact Aid program. We commend you and other Congressional supporters of Impact Aid for securing the fiscal year 1998 appropriation of $808 million, an increase of $78 million over fiscal year 1997.

Thank you for recognizing the importance of this program to the basic education of 500,000 military children and several million of their civilian classmates.

Although the Federal Government has acknowledged its responsibility to provide Impact Aid the program has not been fully funded since 1970. Also, the level of funding has fluctuated from year to year, even with much appreciated Department of Defense supplemental funding for the most heavily impacted districts. Local and state taxpayers are bearing an increasingly larger part of the burden for Federal students.

I must also note that a DOD supplement of $35 million was authorized for fiscal year 1998, but was not appropriated.

Fiscal year 1998 Impact Aid appropriation was generous by the standards of previous years. We know this increase will enable districts educating military children to serve all their students more effectively. Because Impact Aid dollars are targeted where the Federal responsibility is the greatest under the law.

Impact Aid goes directly to school districts, with no strings attached. The local community, the people who have the greatest stake in the quality of education in their schools, decides how these funds will best serve the needs of their students.

Continued consistent funding at or near the authorized level will help these districts plan for the future and budget for special education, technology, transportation, programs to raise standards, and salaries high enough to keep quality teachers. Impact Aid helps these districts approach the level of educational opportunity available in non-impacted districts, even though they do not have the access to the same kind of tax base.

Nothing is harder for the heavily impacted districts to fund than major construction and maintenance projects. Attachment A of my written testimony illustrates some typical

construction needs. These districts often find it difficult to float bond issues or take advantage of states' offers of matching funds. They often must defer routine repairs and maintenance when they have to buy textbooks or computers or other new technology.

But children need safe, structurally sound buildings in which to learn. School construction funding, especially for districts least able to raise money in their own communities, must be a priority. We are grateful for the high level of funding for fiscal year 1998 which allows continued impact aid for the Military B students, the children of military members living in the local civilian community. Large numbers of transient military children do have an impact on a district, even when their parents pay real estate taxes. Unless residing in a legal domicile, military members often do not pay many of the other taxes that States and localities use to fund education. Districts with transient populations need more staff to evaluate and quickly place children in appropriate educational programs, provide remedial help if necessary, and manage the flow of student records in and out of the district.

We ask that you continue to recognize the Federal responsibility to provide funding for military children living off the Federal installation.

Military families list education as one of their most important quality of life concerns. Military commanders know that worries over the education of their children affect the morale and retention of their personnel. In this age of increased accountability, military families hold their children's schools to a higher standard than any State does. We insist that schools prepare our children to enter school at our next assignment, no matter where in the world that might be, with the skills and knowledge necessary to succeed. Military families expect our children's schools to have the resources to meet that standard.

School districts have accepted the responsibility to educate military children. The Federal Government must provide the resources it has promised to support that education.

[The prepared statement of Joyce Wessel Raezer follows:]

[Pages 1275 - 1281--The official Committee record contains additional material here.]

Mr. Porter. Mrs. Raezer, I couldn't agree more. It seems to me if there is anything that ought to be an entitlement in our system as something that the Federal Government is obligated to pay, rather than subject to appropriations each year, it's impact aid. Yet this is one that isn't an entitlement, and unfortunately one that most Members of Congress don't have. Maybe there are 120 or 125 Members that have impacted schools in their districts. That means there are 300 Members, let's say, that don't know anything about the program. It makes it very, very difficult to get the support that we need for the Federal Government to meet its obligation.

I happen to have the largest primary naval training facility in the world in my district. I have a school in North

Chicago, Illinois that is impacted just about 50 percent, and believe me, it is essential aid for that school system. If it wasn't there, the school system couldn't exist, to begin with.

Also the point that you made about the impact on local taxpayers. If the Federal Government doesn't meet its obligations and responsibilities, local taxpayers get angry at the military families, who have nothing to do with it, and the kids who have nothing to do with it, and it creates the kind of situation that is very destructive of learning and good relationships between people and kids.

So I think this is a very high priority. We've done our best to come closer to what the Federal Government ought to be paying and will continue to do our very best to put it at a high priority.

Ms. Raezer. As I said, we do appreciate your efforts and your advocacy for this program.

Mr. Porter. It's enlightened self-interest in my case.

Ms. Raezer. Well, it is in ours, as well.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness]

Tuesday, February 3, 1998.

WITNESS

FRANCIS J. DAVIS, JR., REFLEX SYMPATHETIC DYSTROPHY SYNDROME ASSOCIATION OF AMERICA

Mr. Porter. Francis J. Davis, Jr., Co-founder and President of Reflex Sympathetic Dystrophy Syndrome Association of America, testifying on behalf of the Association.

Mr. Francis Davis. Good afternoon, Chairman Porter, ladies and gentlemen. I am here on behalf of the efforts of a Ms. Donna Feldman, one of your constituents from Deerfield, Illinois. Again, I am President of Reflex Sympathetic Dystrophy Syndrome Association of America. We are a national organization with over 2,000 members, in every State of the Union, and I am also speaking for the estimated 6 million to 10 million sufferers of this debilitating disease.

My mission is to request that you consider inclusion of this dread disease into the rolls of the Social Security Act. Reflex Sympathetic Dystrophy, which we'll call RSD from here in, is a debilitating disease that presents the following trauma. It was originally described in the 1850s by a Doctor Weir Mitchell while treating Civil War soldiers. Dr. Mitchell noticed that many were not responding to treatment following gunshot wounds. Even today, RSD is often misdiagnosed and many of its patients are accused of being fakes, as they suffer from excruciating pain.

While medical advancements abound, RSD goes waiting for protocols, diagnoses, and treatment. While many RSD patients are diagnosed and treated and respond successfully, just as many go through the four stages of this disease and become dependent on the system. It is these fellow sufferers that I represent today.

RSD, a disease of the autonomic nervous system, is a significant cause of chronic pain. It can arise as a result of injury or illness, but can become a primary illness in itself. It is a poorly understood dysfunction of the nervous system and it usually occurs after surgery or injury. The injury may not be apparent, such as a heart attack, repetitive stress, or a minor fall. The most significant onset characteristic is the patient's experience of burning pain, swelling, and loss of motor function, far out of proportion to the physical findings. Skin changes, muscle spasms, tremor, or atrophy can all be present. The pain is severe, said to be the worst pain humans can endure. RSD impairs memory and concentration. Also, the pain does not respond to conventional medications.

A patient with advanced RSD cannot perform substantial gainful activity, including intellectual work, probably for the balance of their lives, and certainly for the 12 months required by the Social Security Act. An advanced RSD patient spends their day contemplating pain relief.

Our members have waited an average of two to three years to achieve benefits from Social Security, far too long, as most of these Americans do not have alternate income. Many RSD patients have lost their homes while waiting for benefits that they justly deserve. Any expediency to the process greatly helps these sufferers.

I humbly implore you to give this your consideration. These patients are only asking for their just due. These are proud Americans, formerly self-sufficient.

Thank you, sir. Do you have any questions?

[The prepared statement of Francis Davis follows:]

[Pages 1284 - 1285--The official Committee record contains additional material here.]

Mr. Porter. I do.

Mr. Davis, if I understand you correctly, your testimony aims at making this disease eligible for Social Security disability, is that correct?

Mr. Francis Davis. That's correct.

Mr. Porter. The difficulty is that this subcommittee has jurisdiction over Social Security only to the extent of its administrative expenses appropriation. The subject matter of a disability claim would have to be addressed, I would assume--and the staff could correct me if I'm wrong--but addressed through Ways and Means, because the program is an entitlement. Therefore in our budget, while you'll see a line item for it, it would be there as a mandatory appropriation, the benefits themselves. So we really don't have jurisdiction over the subject matter. If you were talking about research, of course, we would, but not in the case of making this a recognized subject for disability benefits.

Mr. Francis Davis. I see. I understand.

Mr. Porter. So I'm afraid you're also going to have to testify before Ways and Means.

Mr. Francis Davis. No problem.

Mr. Porter. Thank you for being with us.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness]

Tuesday, February 3, 1998.

WITNESSES

BRENDA HURST
WILLIAM DAVIS, AMERICAN VOCATIONAL ASSOCIATION

Mr. Porter. Brenda Hurst, president of the American Vocational Association, accompanied by William Davis, Chief Executive Officer, Pulsar Data Systems, Inc., testifying on behalf of the American Vocational Association.

Ms. Hurst and Mr. Davis.

Ms. Hurst. Good afternoon, Mr. Chairman. I am Brenda Hurst. I am president of the American Vocational Association, and Special Populations Coordinator at Dobyns-Bennett High School in Kingsport, Tennessee. On behalf of AVA's 38,000 members, thank you for allowing us to be here today.

To succeed in a technological workplace, students need academic and technical skills that are provided together through vocational-technical education. We serve high school students, post-secondary students, as well as welfare recipients and college graduates seeking the academic and technical skills they need to achieve their careers.

To serve our students better, AVA has established a National Business Education Partnership. We're working with such partners as Microsoft, McDonalds, General Motors, Ohio State University, to help ensure a highly skilled workforce and maintain a globally competitive economy.

We are so proud that one of our partners, Bill Davis of Pulsar Data Systems, is here with us today to discuss the importance of vocational education.

Federal support for vocational-technical education provides critical funding for program improvement at the local level. Therefore, AVA respectfully requests at least a 10 percent increase in funding for vocational-technical education.

Thank you, and with your permission, I will turn the remainder of my time over to Mr. Davis.

Mr. William Davis. Good afternoon, Mr. Chairman. It's an honor to be here today. I am founder, president, and CEO of Pulsar Data Systems, an information technology company headquartered in Lanham, Maryland, in Congressman Hoyer's district. Pulsar has 180 employees and has an additional office in Congressman Bonilla's home town of San Antonio, Texas. We have been recognized by USA Today as one of the top black-owned industrial services companies. We also have been recognized locally as one of the fastest growing companies in the D.C. area. In fact, we are now the fifth largest minority-owned company in the U.S.

The success of my business depends on a number of factors, but none so important as the quality of the workforce. Education is, in a very real sense, a business partner of mine. I want this to be a healthy and prosperous partnership for all

involved.

What is being taught in schools must be relevant to opportunities in the workforce. We are working with AVA to meet the top challenges of a rapidly changing workplace and address the needs of students with varied career goals. Leadership is critical at this juncture because we have serious shortages of skilled workers in America. More than 190,000 IT jobs are unfilled today because of a lack of qualified applicants. We need software engineers with advanced degrees, but we also need technicians.

In many industries there are thousands of highly paid jobs for people with a combination of academics and technical skills. I applaud AVA support of policies that strengthen the academics taught in vocational-technical education. Watered-down courses will no longer suffice.

At the same time, we must also strengthen the technical focus of these programs. Without technical skills, students will not be qualified for the jobs of today or tomorrow. For those who go straight to work after high school, this type of education could not be more important.

Our shortage of skilled workers is startling, yet it reveals incredible opportunities for today's youth if they have the right kind of education. Pulsar's future is tied directly to America's students, and we are continually looking for ways to help them create their own future success.

In partnership with AVA, Pulsar is working to provide the latest IT solutions to vocational-technical schools across the Nation. In return, Pulsar has established a scholarship fund for students and teachers. These scholarships will provide incentives for students to pursue the educational pathways needed to enter the IT field, and will provide teachers with the training that they need to deliver academic and technical skills to our future workforce.

This effort holds much promise, but we cannot do it alone. We hope other companies will join with us as this effort grows, and we hope that the Federal Government will recognize its continued role in supporting vocational-technical education. Congress should view this not as an expense, but rather as an investment.

On behalf of my company, and with a strong personal conviction, I urge you to support AVA's requested increase for vocational-technical education. This program sparks in countless students the drive to stay in school and pursue further learning. Vocational-technical education gives industry the key to our prosperity, competent and skilled workers, and it creates for our Nation its individual citizens' greater hope for a bright future.

Again, thank you for this unique opportunity. I also want to thank AVA for sharing its few moments of time here with me today. I would also be happy to answer any questions.

[The prepared statements of Brenda Hurst and William W. Davis, Sr., follows:]

[Pages 1289 - 1302--The official Committee record contains additional material here.]

Mr. Porter. My question is, how come you don't have a facility in my district? [Laughter.]

Mr. William Davis. We do work in Chicago with a minority-owned company, Nexus Unlimited.

Mr. Porter. We would welcome you.

This is a question for either one of you or both. Is there overlap between vocational education and school-to-work programs?

Ms. Hurst. There should not be. I would not sit here and tell you what every school district is doing. If the school-to-work program is operating as Congress had intended it to operate across our country, there should be no overlap of the program.

Mr. Porter. Okay. Where do they leave off and you take up, or vice versa?

Ms. Hurst. In most school districts I think we will find that the school-to-work programs, school-to-career, education edge, whatever school districts are preferring to call their program, it is across the board for all K-12 students. It is exploratory. There's a lot of job-shadowing. It's mentoring. It's an awareness program for all students. It's not a dictatorial program; neither is vocational education. There is a belief among those that in a school-to-work program people are being told what careers they should go into for the remainder of their lives. For example, yesterday was National Job Shadowing Day. Many students across this country had the opportunity to select from a number of employers, a number of professions, and go into the business with a professional on an exploratory basis, in a limited amount of time, to follow them around and to shadow them for that day, to see what their jobs are like.

So it's really an awareness program.

Mr. Porter. So it's more of a career awareness, opportunity awareness kind of thing?

Ms. Hurst. Yes, for all K-12.

Mr. Porter. Right. Right. Okay.

Ms. Hurst. And even in the elementary schools you may have a program where you're studying what a particular bacteria is, and then a teacher would get into exploring what kind of jobs you would have available in this country if this is what you were doing, what courses you would have to take, what academics would you need, what skills, how much college work, etc.

Mr. Porter. This morning we had Lynne Cheney in to testify, the wife of our former colleague, Dick Cheney, who herself has a very exemplary public career. She testified on behalf of the American Enterprise Institute, Mr. Davis, that we are tending to push kids way too early into career paths, and not giving them the kind of broad education that makesthem happier human beings in the long term, better citizens, and the like.

Do you have any comment on that?

Mr. William Davis. My only comment would be that I have five children; my youngest is 23. I would like to think that they've had choices as opposed to being pushed. They've been able to look at alternatives, not because of anything that I have or don't have, but more in line with how they themselves are influenced by peers and by others in terms of what's

available.

So I don't think we push too early. I think what we should be doing more of is giving the kids and students--we do a lot in K-12 from a standpoint of laboratories and the like, computer labs, and installing them and supporting them--I think they should have the opportunity to see what's available so that as they start making those decisions, whether they want to be a fireman or want to be a computer expert, they should have that choice earlier to really start pursuing it earlier, if that's what they choose, or at least to see what's available.

Mr. Porter. I want to thank you both very much for coming to testify. Thank you so much. I learned a lot.

Tuesday, February 3, 1998.

WITNESS

PHILIP FURMANSKI, NEW YORK UNIVERSITY

Mr. Porter. Dr. Philip Furmanski, Dean, Faculty of Arts and Science, Chairman and Professor, Department of Biology, New York University, testifying on behalf of the university.

Dr. Furmanski.

Mr. Furmanski. Thank you, Mr. Chairman. My name is Philip Furmanski and I am speaking on behalf of New York University as Dean of its Faculty of Arts and Science. I appreciate this opportunity to discuss a scientific project which addresses this committee's programmatic and research priorities. We applaud the committee's emphasis in last year's appropriations measure for the Federal Government to support ``research in the area of brain development, mechanisms that underlie learning and memory, the acquisition and storage of information in the nervous system, and the neural processes underlying emotional memories as they relate to intellectual development and cognitive growth.''

We believe that such a national investment into research on the mind and brain will repay itself many times over. To help implement the committee's goal, NYU is undertaking to establish a Center for Cognition, Learning, Emotion and Memory. This center will conduct research along a new paradigm that will push the frontiers of understanding of how the brain develops and functions, and how aging and brain disorders can erode our ability to learn, think, remember, and mature as productive members of family and society.

In addition, the center will help train the next generation of interdisciplinary brain scientists.

To establish this interdisciplinary center, NYU is seeking support to expand research programs, attract investigators from the disparate disciplines that are required, and provide the technical resources that are necessary to create a premiere world-class scientific enterprise.

As you know, traditional funding sources cannot underwrite the establishment of a new cross-disciplinary area of scientific study, particularly one that includes research and teaching and reaches across fields as diverse as biomedicine, psychology, education, computer science, and cognitive science.

The research in this center will have enormous implications

for education, health care, and job training. As one example, research on attention and retention will be useful in designing programs for early childhood intervention. The center's research will help us better understand how children learn at different stages with different cognitive styles; how parents and teachers can accommodate these styles; and how educational technology can be harnessed to stimulate interest in increased retention.

The research need is clear. Many educational reforms are being introduced as we speak without the advantage of an understanding of some fundamental processes that lead to learning.

Second, our research will investigate how memory is altered by aging and by diseases like Alzheimer's, and how biological malfunctions in the educational and emotional system can cause disorders like phobias, panic attacks, and post-traumatic stress. Research into the biology of fear will help us understand the origin of our emotions, how emotional conditions arise, why are they so hard to control, and ultimately how we can prevent and treat emotional disorders.

Finally, research on cognition will impact adult learning and job training programs and help rationalize the way we train new workers or retrain workers in emerging new technologies.

New York University is well positioned to create and operate this major national cross-disciplinary research and training center. The largest private university in the United States, with over 49,000 students and 13 schools, NYU has outstanding researchers and well-established strengths in neurobiology, cognitive science, neuromagnetism, behavioral neuroscience, educational psychology, mathematical modeling, and computer simulation. With these strengths, NYU can create a distinctive center that will produce a new understanding of the brain and new ways of using that knowledge to improve human health and welfare. Our faculty are already widely recognized for their research on memory, learning, motivation, and language acquisition, and NYU is internationally known for its studies in vision, a key input to learning.

NYU is the leader in new studies on the biological basis of emotion. These studies have important implications for learning and memory and control certain harmful emotional states.

As we complete the ``decade of the brain,'' NYU, through this new center, is poised for leadership in accomplishing the aims of this important initiative and the goals central to national priorities. I believe that we are in a special situation among universities to bring these strengths in so many varied disciplines together to attack these crucial issues, and then to disseminate the results for the benefit of the American people.

Mr. Chairman, this concludes my testimony. I thank you for the opportunity to appear before you today. Also let me add my appreciation as a researcher and an NIH grantee on behalf of all the American people for your leadership in biomedicine in this country.

[The prepared statement of Philip Furmanski follows:]

[Pages 1306 - 1314--The official Committee record contains additional material here.]

Mr. Porter. Dr. Furmanski, let me thank you for coming to testify on such an important subject.

You might be aware that we had Dr. John Sarnow of the New York University Medical Center up to testify last fall, a special panel that we convened on the ``mind-body connection,'' for want of a better term, which is not the subject that you're testifying about, but related in a way. He did an excellent job in representing the university, as you have done today, so we thank both of you. Thank you for being with us.

Mr. Furmanski. Thank you very much.

Tuesday, February 3, 1998.

WITNESS

DR. JULES HIRSCH, M.D., AMERICAN SOCIETY FOR CLINICAL NUTRITION

Mr. Porter. Dr. Jules Hirsch, M.D., Past President and Public Affairs Committee Member, Rockefeller University, New York, testifying on behalf of the American Society for Clinical Nutrition.

Dr. Hirsch, good to see you.

Dr. Hirsch. Thank you very much, Mr. Porter, for the privilege of appearing here this afternoon. As you have stated, I am Jules Hirsch, a research physician and professor at Rockefeller University. For a number of years I served as the physician in chief of the hospital at the university, and today I represent the American Society for Clinical Nutrition.

I must say very feelingfully and completely truthfully at the outset that there isn't a member of this large American Society of Clinical Nutrition that we have that isn't extraordinarily grateful to you personally for your championship of the NIH over what we considered were going to be very lean years, and indeed were lean, but nevertheless were sufficiently well-supported by you and your colleagues to keep the scientific establishment going.

We have a very unusual mission. It's the mission of expanding nutritional sciences and the understanding of nutrition sufficiently to make this useful as a technique of prevention of disease, health promotion, and in many instances, treatment of disease. But we have a problem, and what I want to tell you about very briefly this afternoon is the specific problem that we have. It is more fully documented in the written testimony that you will receive, but let me do this in just a very brief fashion.

Let me begin by pointing out something that we all know but maybe we should emphasize. We live in a very remarkable moment in the history of biologic science. In great measure this comes about because of what NIH and the support of this committee and the previous committee individuals have supported. We now know the blueprint for the structure of living cells, encoded in DNA, and that single piece of information has put biologic science on a footing that it has never had in the past. But what is happening with this is somewhat reminiscent of what

goes on with computer science and computer information. Things are moving so very, very quickly that from week to week new and extraordinary events are occurring in how this information is processed and contained within the cell. It began some years ago by getting chunks of the pieces of information, the genes, and understanding their aberrations and relationship to specific diseases by studying people with the diseases, and normal members of their own pedigree, and putting this together.

Now a really astonishing thing is just on the horizon, and that is the possibility that on something akin to a computer chip we will have the entire human genome--not of all people, but specifically of each individual, so that as though you were going to the physician to get a Smack-20 and find out what your blood sugar is and your sodium and this and that, now you're going to get a piece of information in the very near future of your entire genome, the total blueprint with which you were born that sets the stage for human individuality.

Now, we know that these genomes are very different from person to person and, except with identical twins, they are what makes for biological variability. What then happens is that this genome is expressed over time by virtue of the chemical environment in which we live that makes us, finally, the individuals that we are.

Now, the most important aspect of that environment, and in its chemistry, is nutrition, because the materials that we eat bathe these cells and guide the pathway toward growth and development.

So to put this wonderful new information of molecular genetics to work so as to optimize health and to prevent disease, we need as much understanding of the variability of physiologic and biochemical processes and how they respond to illness as we do to the nucleotide codes. In other words, we are born with a blueprint, but that is not ultimate destiny. We are not imprisoned in that forever. There is the opportunity of growth and development, and we must understand how this works, and nutrition figures very prominently in all of this.

What we need now are scientists who study subsets of people who are either alike or not like each other in terms of physiology, susceptibility to illness, response to foodstuffs, so we learn not only what is unique about their DNA but, most importantly, contrariwise, why--with a given DNA constitution--they turned out so differently from each other.

So at last we are beginning to think of a synthesis, an integrated biology, in which DNA structure is not the ultimate and exclusive determinant force which places us in an inevitable chain of development and disease or health, but rather a rich source of chemical understanding to be tapped and understood and known as to what makes us the individuals that we are.

Regrettably, and here is the problem, as this new information rushes headlong into these deep levels of comprehension, the understanding of man in terms of response to environment and in terms of susceptibility to disease is not as much developed as molecular genetics. It is very likely that diseases such as diabetes and cancer, which have genetic determinants, may not be the result of a single gene defect,

but rather very subtle alterations in the functioning of many genes, then acted upon by our nutritional environment.

We have a scarcity----

Mr. Porter. Dr. Hirsch, I am sorry to have to interrupt. I have a meeting I must go to at 4:00 o'clock and I'm going to ask Mr. Dickey to take the chair, and then you can proceed.

Dr. Hirsch. Thank you.

Here, Mr. Dickey, is where our problem is. We have a scarcity of the clinical scientists who can help us understand disease and the operation of the body at this level of integration. Such scientists must, on the one hand, be able to reach back and make use of the fundamental molecular genetic map that exists in each individual, but also must include research physicians who can evaluate the entire organism for the ultimate environmental and nutritional interactions that create an illness or a wellness.

The ranks of these clinical investigators have beendecimated at NIH and across the Nation. The reason for this is that our brightest young physicians are driven, on the one hand, into the depths of molecular genetics, or on the other hand, into the all-important delivery of health care. And this middle ground of clinical research is disappearing.

Often we are confounded by newspaper reports of ``eat fat,'' ``don't eat fat,'' ``more cholesterol,'' ``less cholesterol.'' The public gets totally confused. These reports are all true; they are basically correct. The issue is that they are a single recipe, a single prescription for all human beings, and human beings are extraordinarily different, and it is the business of nutrition and clinical nutritional science to give us the prescriptions for each of us, person by person, from the understanding that comes at this kind of level.

Mr. Dickey [assuming chair]. Dr. Hirsch, let me ask you a question.

Would you concede that good health could be the object of monetary incentives?

Dr. Hirsch. Yes.

Mr. Dickey. Have you ever seen it work, or seen it being applied?

Dr. Hirsch. That good health can--can you give me a----

Mr. Dickey. Well, let's just say--you're talking about nutrition, but let's just say we're talking about the loss of weight. You can do that through proper nutrition. Have you ever seen a program that paid people to lose weight?

Dr. Hirsch. Yes. As a matter of fact, there have been such programs, with relatively minor degrees of success, I must say, over the long run, the reason being that a lot of the fundamental biology of obesity has not been that well understood. It is this kind of nutritional science that can make the difference for it.

But in the short run, there have been programs--engineered, for example, at the University of Pennsylvania and some other places that come to mind--in which, at least in the short run, it works.

Mr. Dickey. Okay, let me ask it another way, then. How can we encourage people to want to take better care of themselves?

Dr. Hirsch. By understanding the ways in which they have come to do a bad job, because the wrong nutrition that we often

practice comes about by virtue of developmental and biologic events. So for example, children, very early in their development, get set up into certain patterns of food intake and behavior that become increasingly difficult to deviate from. So what we need is understanding of how people have come this way. We've become very disenchanted by lecturing to people about nutrition and trying to have them change their diets. Although some of this has happened, all too little has happened.

So more biologic understanding is required. When I began in the obesity research area, which is my area, it was thought to be exclusively a psychological personal matter. We now know that that's not true. There are fundamental and important biologic determinants that are also at work in this about which we need to know even more.

Mr. Dickey. I think your time has expired.

Dr. Hirsch. My last request is that--we have the mechanisms within NIH for supporting this, but what we need is support specifically of the clinical nutrition research units which tie this information together. And what our organization requests is your attention to the further funding of these clinical nutrition research units at NIH, and the full details are in the testimony.

Mr. Dickey. Thank you, Dr. Hirsch.

Could you give your office number to that lady right there, Ms. Galloway, please?

Dr. Hirsch. I'd be delighted to.

Mr. Dickey. All right. Thank you very much for the time and your commitment.

[The prepared statement of Jules Hirsch, M.D., follows:]

[Pages 1319 - 1331--The official Committee record contains additional material here.]

Tuesday, February 3, 1998.

WITNESS

DR. KENNETH M. VISTE, JR., M.D., AMERICAN ACADEMY OF NEUROLOGY

Mr. Dickey. Next we have Dr. Kenneth Viste, Jr., Immediate Past President, American Academy of Neurology, from Oshkosh, Wisconsin. Did you fly in here?

Dr. Viste. Yes, right down the road from Green Bay.

Mr. Dickey. I've been to Oshkosh. My neck was constantly looking up because of the flights coming in.

Dr. Viste. I live right down the runway from it.

Mr. Dickey. Do you really?

Dr. Viste. Yes.

Mr. Dickey. It's unbelievable.

The American Academy of Neurology. You have five minutes.

Dr. Viste. Thank you very much, Mr. Dickey. It's a pleasure being here today. My name is Ken Viste, Immediate Past President of the Academy of Neurology, Past Chair of Legislation for the AMA, and I currently chair the HCFA Practicing Physicians Advisory Council. I am testifying today

on behalf of the Academy of Neurology, a medical and scientific society representing some 15,000 neurologists and neuroscientists, and on behalf of patients with neurologic conditions.

My testimony will focus on needs in the areas of research related to the brain and conditions involving the brain.

It is estimated that at least 50 million individuals suffer from some disorder relating to the brain. I shall not go into all the numbers, but suffice it to say it is a very expensive proposition, both in terms of monetary means, as well as the human impact.

In my training at Northwestern, neurology was originally thought to be a specialty where it was ``diagnose, and adios.'' We really could do a very good job of diagnosing people--not as good as now, perhaps--but we really had very little in the way of treatment.

Fortunately, this has all changed. In the Nation, particularly those who practice neurology have the Congress and particularly this subcommittee and the NIH to thank for this. There are now many useful and exciting developments related to the treatment of neurologic conditions. Last year, Dr. Zach Hall of NINDS spoke of these breakthroughs in his testimony here.

An expanded research budget for fiscal year 1999 will assist in carrying forward these clinical initiatives.

Mr. Dickey. Excuse me. What is the most common diagnosis in your field?

Dr. Viste. Headache.

Mr. Dickey. Interesting. Thank you.

Dr. Viste. The Academy of Neurology would hope that the NIH budget can be doubled in the next five years. For fiscal year 1999 we would like to see a 15 percent increase for NIH as a whole. In particular, we recommend that the budget of NINDS and the budget for brain research through NIH double over the next five years and be increased to 15 percent in fiscal year 1999. We believe this expansion should emphasize clinical research, given the many opportunities that now exist.

There should also be a commensurate increase in the research management and support budget of NINDS to enable it to effectively manage its initiatives.

Within these increases there are a number of specific initiatives we endorse.

First, we support the recently announced Alzheimer's Disease Prevention Initiative, which calls for an increase in research funding there of some $100 million in fiscal year 1999. A principal focus of the initiative will be on multicenter clinical research and trials.

Secondly, we support initiatives included in the MorrisUdall legislation on Parkinson's Disease.

Third, we support the initiative begun in 1998 to expand the research, prevention, and services in brain injury, including clinical research on treatment and rehabilitation related to brain injury.

Finally, stroke research and education is a major priority for our academy and is an area of dramatic achievement. We support the Heart and Stroke Coalition recommendations for stroke research expansion.

As far as stroke research goes, I think you are aware of a new breakthrough in this past year, t-PA, a clot-buster, something that has been very important in the treatment of heart attacks, but the advent of reversing strokes is now upon us. This is largely through efforts and research of NINDS. NINDS has launched a consortium of all the major interest groups in really trying to bring and elevate, through public education and professional education, brain attack to the same level as heart attack, and I think we applaud the efforts of NINDS. We certainly believe they need the resources to continue this effort, to bring the fruits of this very excellent research and trials to general use in the hopes of decreasing the burden on society of stroke. Certainly we need to do a great deal more in this area, given the 400,000 people a year that are affected by stroke.

In terms of Alzheimer's Disease, there is evidence that Vitamin E, or even ibuprofen, may help people not get Alzheimer's Disease.

Mr. Dickey. In what quantities?

Dr. Viste. Probably 400 milligrams, four times a day.

Mr. Dickey. Of each?

Dr. Viste. No, no, of ibuprofen. Of Vitamin E, 600 units a couple times a day.

Mr. Dickey. I forgot what you just said. Say it again.

Tell me this. Are there any side effects?

Dr. Viste. The ibuprofen could give you a gastric ulcer.

Mr. Dickey. Okay.

Dr. Viste. Vitamin E, probably not, and it's particularly good for potency, as well. That's the main use.

Mr. Dickey. Please. This is Washington. We can't talk about those things anymore. [Laughter.]

Dr. Viste. Okay. In terms of Parkinson's Disease, we support the Morris Udall initiatives. Certainly, scientists in the last year have discovered the gene that causes some forms of Parkinson's Disease, and certainly we support the efforts of the Parkinson's Disease organizations in establishing centers of expertise in this area.

Another condition is multiple sclerosis. There is growing evidence that there are viral triggers that set off multiple sclerosis. We support the National Multiple Sclerosis Society in recommending increased research funding in these areas of opportunity for this disease.

Likewise, for epilepsy, there is a great need, looking at seizures in childhood, special problems with epilepsy among women, and anti-epilepsy drug development.

Likewise, in traumatic brain injury, there is a great deal of opportunity to decrease the burden of traumatic brain and spinal cord injury with appropriate clinical trials.

In summary, we believe that there should be a priority at this time for clinical research, that an increased emphasis in this area really offers great opportunities to improve the health of this country.

Concomitant with this, there are two new initiatives that I should really call attention to: a clinical trial pilot grant program, and a clinical trial planning grant program. In other words, if we're going to move into this area, it is incumbent that we have programs to help people go about doing it

correctly so as to marshall and use our monies as effectively as we can.

I thank you for your attention and suggestions, and would answer any questions you might have.

[The prepared statement of Kenneth Viste, Jr., M.D., follows:]

[Pages 1335 - 1352--The official Committee record contains additional material here.]

Mr. Dickey. I've asked them all. Thank you, Dr. Viste. Good job.

Tuesday, February 3, 1998.

WITNESS

DAVID RHODES, ASSOCIATION OF INDEPENDENT COLLEGES OF ART AND DESIGN

Mr. Dickey. Next we have Dr. David Rhodes, president of the School of Visual Arts, Association of Independent Colleges of Art and Design.

Mr. Rhodes. Mr. Dickey, thank you for this opportunity to testify.

Mr. Dickey. Is it Dr. Rhodes or Mr. Rhodes?

Mr. Rhodes. Just David.

Mr. Dickey. Hi, David.

Mr. Rhodes. My name is David Rhodes and I'm president of the School of Visual Arts in New York City. I am before you today on behalf of the Association of Independent Colleges of Art and Design, AICAD, which is a consortium of 32 institutions that educate more than 30,000 students annually at the collegiate level from all 50 States and more than 70 foreign countries.

We believe that support for art and design education is a sound investment in the quality of American life.

It is a privilege to appear before the subcommittee to discuss support for arts education for children in public schools. In 1994, Congress passed and the President signed the Improving America's Schools Act of 1994. Under Title X, Part D, Arts in Education, the program authorized a program called ``Cultural Partnerships for At-Risk Children and Youth.'' AICAD was proud to be associated with the legislation, which encourages community involvement by colleges and other cultural institutions to promote the arts for children in poverty-stricken neighborhoods. AICAD played a major role in the adoption of this particular provision.

In 1996, the President's Committee on the Arts and the Humanities published a report entitled ``Coming Up Taller'' in which they documented the importance of arts programs to the intellectual development of children, especially for children in high-risk neighborhoods with few cultural opportunities. The report found that ``Community arts and humanities programs provide crucial building blocks for children's healthy development.''

A study by the Port Authority of New York and New Jersey found that the arts and other cultural activities account for at least $9.8 billion a year of economic activity in the New York metropolitan area, and directly and indirectly support more than 107,000 jobs. While the arts experienced a boom during the 1980s, the subsequent bust in the 1990s widened the gap between the cultural haves and have-nots.

The Federal Government has invested in elementary and secondary education when it has been in the perceived national interest to do so. For more than 30 years it has supported those groups that have been historically unserved or underserved, the poor, the disabled, and those with limited English proficiency. As the President's committee has demonstrated, the arts have the ability to help children overcome these initial disadvantages.

In addition, many children don't do well in the traditional classroom setting, where rote learning is the key to success. Without access to the arts, these young people are being short-changed. The real tragedy is that we're failing to take note of what art can do for children by enhancing their creative ability to grasp abstract concepts. In addition, we are failing to equip our children for economic opportunities where the economy is expanding and real jobs exist. This is especially true in New York, but it is also the case in Philadelphia, Baltimore, Chicago, L.A., D.C., and almost any major urban area where arts-related jobs are plentiful and positions for those with a serious arts education often remain unfilled.

Therefore we ask that the subcommittee fund the Cultural Partnerships Program and other programs which encourage colleges and other cultural institutions to work with at-risk children through the public schools.

Mr. Dickey. Excuse me. What connection does thisappropriation have with the National Endowment for the Arts?

Mr. Rhodes. None. The National Endowment for the Arts has very little to do with education to begin with, although they have a program that was enacted by Congress for them to do exactly that. That program was never funded. They have very little programmatic activity within the public schools. This would be separate from and clearly in addition to--and actually, it doesn't appear that the Endowment's mission covers this activity with respect to public schools.

Mr. Dickey. Okay. Thank you.

Mr. Rhodes. As you know, this program also lends itself to distance learning partnerships for communities with sparse cultural resources, which makes it appropriate for rural communities also. Thus these programs, if funded, can enhance the opportunities for students to study the arts with all the attendant benefits, but to do so within a technological framework which will lead to a high degree of computer literacy and Internet sophistication.

I would like to thank you for this opportunity to address you and I would be pleased to entertain any questions.

[The prepared statement of David Rhodes follows:]

[Pages 1355 - 1358--The official Committee record contains additional material here.]

Mr. Dickey. Who censors what the kids receive, as far as education is concerned?

Mr. Rhodes. I'm sorry?

Mr. Dickey. Is there any censorship that goes on with what the kids receive in their education in the visual arts?

Mr. Rhodes. Yes. Good taste. In other words, what the kids receive has to be age-appropriate----

Mr. Dickey. Who decides that?

Mr. Rhodes. The teachers, generally. The teachers and parents. It's a local decision.

Mr. Dickey. Okay. Now, is this the sort of thing where they are actually doing the work, where they are drawing things and painting things? Or are paintings brought to them and explained?

Mr. Rhodes. We would urge that they actually do the drawing and painting, they actually do the exploration, rather than having a static representation of a painting of some note that is then declaimed upon by someone who is an aficionado or a historian.

We believe that to do this they've got to get a little messy, maybe, and from that mess we think something good comes. By way of example, I'm sure you're familiar with cuisinart sticks?

Mr. Dickey. No. I'm from Arkansas.

Mr. Rhodes. They're small sticks that are used to teach mathematics.

Mr. Dickey. Are you saying cuisinart?

Mr. Rhodes. Yes, cuisinart. They are small sticks that are generally in units of one to ten, and they are used to teach mathematics to preschool children. And that activity, that hands-on nature, is what seems to work. I know it did wonders for my daughter when she was three.

Mr. Dickey. Well, just in a nutshell and as your final statement, what is it that the visual arts give to our kids that they need?

Mr. Rhodes. It gives them a sense of being able to create and master their own sets of problems, which are structured in such ways that they blend in with the regular curriculum, so that in fact the overall achievement is enhanced, and at the same time there is a sense of mastery that is gained rather more quickly than sometimes occurs in a more traditional setting.

By way of example, in the Baltimore city high school system there is a specialized English magnet school, a specialized mathematics magnet school, and a specialized art magnet school. The board scores, as you might expect, in the city are highest in English in the English school, and highest in math in the math school. But the second highest in both categories is at the art school.

Mr. Dickey. Interesting. Is that because of the confidence they receive?

Mr. Rhodes. That's a large part of it.

Mr. Dickey. The fulfillment of expression?

Mr. Rhodes. They've got something that they really enjoy doing, so they're there every day. I run a program for at-risk

kids that is funded by the State of New York, and one year, I'd like to say, I had better than 100 percent attendance because I had two kids that were expelled from the school that I was working with, attending that program in the summers every day. They were behavior problems in school, but not in my program.

Mr. Dickey. Well, I saw that in the headlines of the New York Times. You always hear the good things, don't you, in the headlines?

Mr. Rhodes. We try.

Mr. Dickey. Thank you, sir.

Mr. Rhodes. Thank you.

[Clerk's note.--Information required pursuant to clause 2(g)(4) of Rule XI of the Rules of the House of Representatives was not received from this witness or from an entity represented by this witness]

Tuesday, February 3, 1998.

WITNESS

MICHAEL S. LANGAN, NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Mr. Dickey. Next we have Mr. Michael Langan, Vice President of Public Policy and Government Relations, National Organization for Rare Disorders, Inc.

How are you doing?

Mr. Langan. I'm doing just fine. How are you today, sir?

Mr. Dickey. You have five minutes, at least.

Mr. Langan. Well, thank you. I believe, if I'm not mistaken, I'm the last person on this list of witnesses today.

Mr. Dickey. That's correct.

Mr. Langan. For that reason, since I know it's been a long afternoon, you have a copy of my written statement for the record, so I will try to work from my notes.

I will basically say to you, sir, we are very delighted to be here, even though we're last on the witness list, but we're very thankful. My name is Michael Langan. I'm the Vice President of Public Policy for the National Organization for Rare Disorders. I also happen to serve on the executivecommittee of the ad hoc group for medical research funding.

Interestingly, the National Organization for Rare Disorders is actually a voluntary health agency, a large federation. We have more than 140 patient advocacy groups as our members. We represent people with rare genetic diseases. It has been estimated that there are more than 20 million Americans with one of over 5,000 rare--usually genetic--disorders.

These are often known as ``orphan diseases.'' Treatments that are developed, often through the NIH and developed by private pharmaceutical companies or biotechnology companies, are known as ``orphan drugs.'' This issue was addressed by Congress in the early 1980s, looking at it really from a private sector standpoint, that basically it was very difficult for private sector companies to justify a huge investment in studying these treatments for these rare, very small patient populations, and they developed the Orphan Drug Act to give some incentives to the private sector. It has been extremely successful. We have drugs that are approved for safety and

effectiveness and out on the market today that wouldn't have existed 10 or 20 years ago.

Now, Congress did a wonderful job in addressing the needs and sometimes the pitfalls of the private sector market. But throughout the history of the NIH, the National Institutes of Health has been a real place that many people with rare diseases could call home. This is where medicine is taken care of, regardless of whether there's a potential for profit down the road.

But what we've seen, unfortunately, is that very often these diseases still tend to fall through the cracks at NIH. A rare disease, such as Lesch-Nyhan Syndrome, or something called Leukodystrophy, which is commonly known as the ``bubble boy disease,'' some of these conditions may only affect 100 or 200 or 300 patients in the entire country. What we found is that unless there is better coordination at NIH, then very often these researchers who are interested in studying these diseases don't communicate with one another. They don't know if there are any resources out there. They hear all the time that we spend more money on cancer or on Parkinson's or on AIDS, and very often they become discouraged. They don't know that there might be some money available through the NIH, somewhere, somehow, to address the needs of these very small patient populations.

The gentleman before me, the neurologist, mentioned a number of neurological diseases, Parkinson's Disease, Multiple Sclerosis, and others. There are a lot of neurological disorders, too, that exist out there, hundreds, where many people up here on Capitol Hill don't know about them. Very often a lot of people at NIH don't even know about them.

What we are here today for is to ask you and to ask the subcommittee and the full committee to really address these needs through looking at some of the structure and the funding of the structure at NIH, namely, the Office for Rare Diseases. You may be familiar that administratively, there is the Office of AIDS Research, or the Office of Women's Health Initiative, and some other offices that try to coordinate research. This is an office that has been underfunded for many, many years. We are asking this subcommittee to fund it at a level of $10 million next year. Currently it has a budget below $2 million.

But it has done wonderful work, and I would like to mention three things that this office does, and can do in the future even better.

One is to coordinate a number of scientific workshops on these rare diseases. Basically----

Mr. Dickey. You want it to go from $2 million to $10 million?

Mr. Langan. Yes, sir. This has been a sorely underfunded program at NIH, and that is what we are recommending as the patient advocacy community. We recognize that it is hard to achieve.

Basically, some of the activities of this office that should continue and be enhanced are holding workshops, these scientific seminars, where they actually bring the researchers together. So often they can't find patients to even enroll in clinical trials.

Secondly is to continue the creation of a Rare Disease

Clinical Trial Data Base. I got a call just the other day from a woman--I believe she may live in your district, in fact--a woman in El Dorado, Arkansas, who has Addison's Disease. No one, really, in the State of Arkansas, doctors, practitioners, have any idea what Addison's Disease is. It's a rare and serious disease, sometimes fatal if it's not treated. It's an intestinal condition.

I'll try to move on real quickly here.

That's one example; they don't know whether there's even any investigational treatment available from NIH. That's why the role that this office plays is crucially important.

Mr. Dickey. She called you and not the doctor?

Mr. Langan. She called me directly. I don't know if she got on the Internet. She found our telephone number. She basically called our organization to look for some help and some direction to turn in. We definitely headed her in the right direction through this data base.

Mr. Dickey. Can you tell her--it would seem like that it would be an invasion of privacy for me to ask her name and then to call her. It might be offensive. Could you do me a favor and ask her to call me, if she would like to?

Mr. Langan. I sure will.

Mr. Dickey. She'll know how to get hold of me.

Mr. Langan. Thank you. I'll do that, sir.

I think, just to close on one or two points here, I would just like to say that we do join with the ad hoc group for medical research funding and many other groups in advocating for a 15 percent increase in the overall budget of NIH. We feel that NIH is truly a place that rare orphan diseases can indeed call home.

So thank you. If you have any questions, I'd be happy to answer them.

[The prepared statement of Michael S. Langan follows:]

[Pages 1363 - 1370--The official Committee record contains additional material here.]

Mr. Dickey. Thank you. It's quite creative of you to bring up El Dorado, Arkansas. [Laughter.]

Mr. Langan. I just thought about that, actually.

Mr. Dickey. It's a pretty good move.

Mr. Langan. Thank you, sir.

Mr. Dickey. Thank you. Good job.

The subcommittee stands adjourned until 10:00 o'clock tomorrow morning.

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